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ABSTRACT

Intended for parents of developmentally disabled children, the handbook provides information on service needs and services available in Lake County, Illinois. Section I focuses on life course planning with sections of diagnosis and assessment, professionals involved with special education, education for the developmentally disabled, vocational services, and living environments. A second section discusses family support services in the following areas: health care, family counseling, recreation, community services, financial planning, and family planning. Section III, on consumer action, addresses parents and the needs of children at home, parents of children in programs, parents as members of parents' organizations, parents as planners of programs, and parents as legal and legislative forces. A final section describes the causes, identification, and treatment of mental retardation, cerebral palsy, epilepsy, and autism: and considers a noncategorical definition of developmental disabilities. Also provided are a philosophy and history of developmental disabilities services, specifically in Lake County: and a directory of services for Lake County families. (SBH)

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THE WORLD OF THE DEVELOPMENTALLY DISABLED CHILD:

A Parents' Handbook

with directory of services for families
in Lake County, Illinois

by

Marijean Suelzle and Vincent Keenan

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Introduction

The World of the Developmentally Disabled Child has been developed in accordance with the trend towards the provision of community-based services for developmentally disabled children and their families. The format for the handbook and the selection of information to be included evolved from the identification of service needs and satisfactions in a particular community -- Lake County, Illinois. Geographically situated in the northeastern corner of the State, Lake County provided a diverse population in terms of socioeconomic, ethnic and racial, and urban, suburban and rural backgrounds. It also offered a wide range of services to developmentally disabled persons: a major state-operated residential center, smaller private residential programs, two cooperative and one community unit special education districts, workshops, and vocational training. Alternative residential programs, employment opportunities, and family support services were being developed.

The handbook is intended as a prototype for any community defined by the provision of a meaningful and accessible network of services, whether a large metropolitan area or a rural county. We believe the general needs of a developmentally disabled child and the family are the same regardless of place of residence -- life course planning, family support, consumer action, and the establishment of definitions and policies which ensure developmental needs are being adequately met. We have endeavored to provide enough of a rationale for our recommendations that the handbook will be useful for parents outside of Lake County as well, even in its present format. Of course its utility would be greatly enhanced if local references were changed and a local directory of services developed for other communities.

In developing the handbook, information on the networks of services actually utilized was obtained from a 57-page mail survey questionnaire completed by 330 Lake County families with developmentally disabled children 21 years of age or younger. For the purposes of this study, developmentally disabled was defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of the foregoing, and whose handicap required more than 50 percent time in a special education program. We made personal site visits to all of the agencies and facilities identified as providing services to developmentally disabled children in the County. At each site visit we toured the program as well as interviewing at least one direct service professional, administrator, or parent. In the process of collecting this information, contact was made with persons willing to provide editorial assistance. Drafts of all the chapters were critiqued by parents and professionals, and their suggestions for revisions incorporated in the final version of the handbook.

In summarizing the voluminous data we collected for the handbook, some simplifying assumptions had to be made to render the material manageable. We assumed we were writing for parents with a high school education or its equivalent, but without special college or professional training. We tried to provide enough information for the new parent who is just beginning to learn about services available for developmentally disabled children, and for the parent who has some experience but may be looking into the availability of and necessity for a different type of service. We assume initiative on the part of parents. The ideas and suggestions we provide are just beginning leads. Indeed, follow-up projects could involve expanding each chapter to the length of the handbook and even then every aspect of a particular service area might not be fully covered. We assume that if parents are given enough information to know what should be available, they will have the persistence to find a knowledgable expert who can support them in finding the best solution for a particular child's individual needs. We have assumed that the parent who turns to a handbook for assistance will be able to trade emotion for control in the best interest of maximizing the development of their child and of their family unit.

We assume frequency in change of services offered and staff turnover. Therefore, we have included few specific names in the handbook. We have tried to include only programs and organizations which have been in existence for a long enough period of time to assume stability. Therefore, the handbook should remain useful if addresses and telephone numbers change because new listings should be readily obtainable from the yellow pages or telephone directory service.

We have tried to emphasize what parents can do as individuals and those areas where collective action is required. This emphasis reflects our philosophy that parents are the most important members of the team of professionals working with developmentally disabled children. Parents are the only members of that team with a life-cycle perspective and involvement at any one time and over time. Therefore, parents must become the real coordinators of services to maximize benefits to children.

Marijean Suelzle, Ph.D.
Vincent Keenan

Northwestern University
Evanston, Illinois
September, 1979

LIFE COURSE PLANNING

Throughout the developmentally disabled child's lifetime, evaluations of abilities and disabilities determine which school programs, medical treatments, and/or any kind of special help will be received to stimulate development. Life course planning involves diagnosis and assessment of the disability, encounters with a variety of professionals, educational programs, vocational services, and the selection of an appropriate living environment.

Extensive medical, psychological and educational testing is done when a child is young to determine what the disability is, and what can be done to help. The best evaluations are performed at large hospitals, clinics and programs which are able to draw together many different professionals. Diagnosis by a single doctor or psychological test is usually not adequate for assessing the child's abilities. For example, a child who seems to have a developmental delay could be diagnosed as retarded on the basis of a test, when the problem might be that the child has a hearing loss. Deciding on which clinic, hospital, or program to bring the child to involves several questions. How much will the assessment cost? How long will it take? Where are the clinics? Which provide the best treatment for a particular child? These are the kinds of questions answered by the Chapter on Diagnosis and Assessment.

Special educational programs involve a wide variety of specialists. Too often parents have little idea of how these specialists work with their children and are uncertain about what questions to ask to obtain information. Since titles can be confusing, the Chapter on Professionals provides brief descriptions of the specialized training and job expertise for each profession. To avoid fragmentation and lack of continuity it is best if parents personally know all the professionals involved with their children and can provide accurate and up-to-date records as requested. The Chapter provides suggestions about the ways parents can work with professionals, both giving and receiving helpful information, to maximize children's development. This is best accomplished by maintaining continuity of philosophy and practice between home and school.

Special education for the developmentally disabled is available, by law, for children ages 3 to 21 with early intervention programs serving the population from birth to 3 years. The range of services offered is broad. Children move between different types and levels of special education as their needs and abilities change. The Chapter on Education describes the services provided for different age groupings: early intervention, preschool/primary, secondary, and transitional to adulthood. All the years spent in preparation will have the outcome desired if parents understand and support the relationship between school curricula and developmental goals. Education should be directed towards maximizing the potential for a satisfying adulthood.

The goal of education is to provide the developmentally disabled with the skills and training which will enable them to function as independently as possible as adults. Children are never too young to be taught the positive work habits and attitudes of dependability, promptness, following instructions, courtesy, and cooperation. Just receiving a diploma with no job or plans for further training limits opportunities for independence and continued development. Vocational training should begin in school. The Chapter on Vocational Services discusses the next steps including work activities programs, sheltered workshops, and job opportunities under various degrees of supervision. Employers need to be educated too. Community acceptance is a prerequisite to meaningful employment opportunities.

It is usually very difficult for any parent to have their child leave home, regardless of the child's age. For most families, the issue will be considered as the period of formal schooling draws to a close. Parenting, through the provision of emotional and often financial support as well, continues throughout the lifetime. The Chapter on Living Environments outlines the types of public and private programs supported by state funding, provides suggestions for evaluating living environments, and discusses the meaning of establishing independence. The groundwork for an alternative living situation should be laid in advance as the end result of life course planning.

Diagnosis and Assessment

Throughout your child's lifetime, evaluations of abilities and disabilities determine which school programs, medical treatments, and/or any kind of special help will be received to stimulate development. Extensive medical, psychological and educational testing is done when a child is young to determine what the disability is, and what can be done to help. Professionals interpreting the testing results will suggest a certain program or treatment plan. Follow-up evaluations, usually not as extensive as the initial one, are done at regular intervals during the child's lifetime to check development. The follow-up tests check to see if the treatment that is being given should be continued, changed or stopped.

Schools do not usually provide medical examinations and often assume that parents have already taken care of the medical evaluation or other diagnosis and treatment that the child requires. Therefore, it is up to you, the parents, to get the medical evaluation for your child.

The first person that you may consult could be your family doctor. A doctor with a general practice may be understanding, but may not have particular expertise in the specialized area of handicaps and the special physical, psychological, and educational needs of special children. The best advice may be to send you to a specialist who deals with handicapped children daily and knows their needs. Your family doctor may be able to recommend a diagnostic clinic of a teaching hospital or a university clinic.

The best evaluations are performed at the large hospitals and clinics able to draw together many different professionals and personal approaches to your child's assessment. Diagnosis by a single kind of doctor is usually not adequate to answer all needs. Testing by a multidisciplinary team of doctors can help to indicate specific disabilities that might not be observed by just one professional. For example, a child who seems to be uncooperative in school or at home could be diagnosed by a psychologist as having an emotional problem, when he actually has a hearing loss. A multidisciplinary testing expands the number of professionals and personal approaches to your child's assessment.

The large clinics have many different professionals that you might come in contact with. They range from doctors of many different specialties to psychologists, social workers and psychiatrists, as well as speech therapists, physical therapists, occupational therapists, inhalation therapists, nurses and possibly a whole range of medically based technicians whom you may never meet, such as nutritionists, lab technicians and endocrinologists.

Many times the diagnosis is a combined effort of the whole team. The team will meet at what is called a "staffing". At these staffings, each of the persons who is involved in your child's case submits a written report on your child. One of the professionals will be the case coordinator -- the person in charge. The case coordinator will summarize the findings of the tests given by the professionals and the recommendations for treatment, schooling, or whatever. Each professional knows the others' fields well enough to ask intelligent questions about recommendations made by the professional. This process assures the child the best assessment possible.

Deciding on which clinic or hospital you should bring your child to involves several questions. How much does the assessment cost? How long will the assessment take? Where are the hospitals? Which provide the best treatment for your child?

One of the best means of choosing a clinic is to ask friends, school personnel, or parent organizations which clinics they have heard of and what results they have had with these clinics. Parent organizations (such as, local chapters of the National Association for Retarded Citizens, or the parent groups of local schools for handicapped children) are good resources because you are sure to find many persons who have been to many different clinics in your area. By listening to their experiences you can probably decide which one would be best for your child as well as prepare yourself for the experience. In the directory at the back of this manual, we have listed many of the different clinics found in Chicago and the northern suburbs. Estimates for treatment costs are just that, estimates. The cost of treatment is increasing yearly with the spiraling costs of equipment and professionals. The listings will help you to find out about different programs and what they offer, but we still suggest that you talk to other parents or parents' groups to get a fuller idea of what each clinic's approach and treatment plans are.

As parents, you can prepare your child and yourself for the evaluations in several ways. First, you will be asked about the child's medical and developmental history. When did the child first begin to turn over? Did you notice anything different about this child as compared to your other children? The person who will be asking you these questions, usually called an intake worker, is trying to get an idea of how your child has developed. The intake worker will also ask you questions about other family members (brothers, sisters, grandparents, aunts, and uncles) to see if heredity has had any effect on your child's health. The reason for compiling a family history is not to place the blame for the child's disability on someone, but to see if the information about your families can help them pinpoint the nature of your child's disability, and hopefully prepare a better treatment plan. You can be prepared for these family history questions by bringing with you to the first meeting any results from previous tests that were done on your child, any personal records you might have kept on your child's growth and development, and any ideas or memories you have about family members who had unusual diseases or handicaps.

The first meeting at the clinic will probably be very important to you in terms of what the evaluation can do for your child and how much it will cost to do so. Most clinics will charge you a fee for this first meeting but you should find out at this meeting exactly in which tests your child will be involved. Ask how long the evaluation process will take and how much the anticipated cost is going to be. Find out if your health insurance covers any of the testing; some policies will cover all or part of the evaluation costs. If you must pay for all or part of the services, ask to talk to the billing department of the clinic or hospital and see what financial arrangements can be made (for example, installment payments).

You may not want to have the testing done at the first clinic that you go to: the costs may be too prohibitive, or you may not agree with the philosophy of the program. For example, the program may be oriented toward curing your child's disability through emotional kinds of therapies and you may be seeking a program that will be oriented toward educational therapies. Looking around at a few clinics is probably a good idea, but you must weigh the costs of all those initial meetings and the time it takes to travel to all those clinics. It is not an easy decision and you may often be frustrated. Take time to evaluate the information you have received and to discuss it with others.

As parents you have a right and an obligation to know about any procedures before they are undertaken with your child. You should understand what you are agreeing to and the reasons the procedures are necessary. You should have an idea of what results are expected and what side effects are possible. During the initial interview the professional you are talking with should be able to provide you with information that will answer all these issues.

You can prepare your child for the diagnostic procedures. If need be you can ask suggestions on how this can be done at the first interview. If the professional you are dealing with is unwilling or unable to provide you with useful guidelines then request an interview with someone else. When you are explaining to your child about the tests do not tell the child too much potentially frightening information at once. Small doses of information work better. The goal you are reaching for is that your child will be prepared enough to cooperate during the testing.

The actual diagnostic process can take from two weeks to six months depending upon the clinic or hospital that you go to and the amount of testing done on your child. Testing is almost always done on an outpatient basis. You will most likely have to come to the clinic several times during the evaluation process to get all the testing done. Most clinics will try to schedule as many appointments as possible on one day so that you will make the best use of your time. Working parents should take this into consideration and beware of the clinics or hospitals that make appointments several months away or on too many different days. Try your best to get an appointment schedule that does not overtax you, yet is still flexible enough for the clinic's tight schedule.

Your child will take a series of tests that will try to evaluate disabilities and potentials for development. A helpful premise to start off with is that neither the professionals nor the tests are perfect, but a combination of competent technicians and sound tests will provide you with reasonable answers. The clinician may be using professional terms ("test jargon") to explain what the test is all about. Specialized words and labels identify many different problems in what are precise terms for the profession. You should ask to have such words explained to you in plain English. In medical and psychological tests, the tester does not look for an exact score but rather at a general range of scores. The exact scores will vary, even on the same test. Evaluations of your child in any areas will not be on one test only, but on a series of tests that will indicate generally at what level your child is functioning now, and what level might be achieved in the future. There is no guarantee that what the clinician predicts will come true. It is only the best estimate at that time and can be helpful in setting short- and long-range goals.

The usual procedure for informing you of the diagnosis is through the final meeting. There you will meet with either one professional who tested your child, or with a group of them. As discussed before the professionals have already had a staffing and will have come up with a diagnosis and recommendation for treatment or placement of your child. At the time of the meeting you should receive a written statement of all the tests done and all the professionals seen by your child. The results should be written in a language that you understand. Often the raw scores of the tests will not be included because they have very little use for you and could be misleading. The person or persons with you have a responsibility to give you a clear understanding of what the diagnostic tests are and what the scores mean for your child.

Some basics you will want to know: Is my child in basically good health? What can be expected in terms of school performance? How does the child feel about the problem? What specifically can be done about the handicapping condition? How will the child's disability be minimized at home and at school? All of these and other questions are concerned with what is the child's problem. Do not take a one-word diagnosis for an answer. Being told that your child has Down's Syndrome is interesting but it does not give you any idea at what level the child is functioning, nor what you can expect for the future.

When you leave the final session you should have a written statement of the testing procedures and results that your child has undergone and a good understanding of those procedures and results. You, the parent, are the child's best partner. You are the most important part of the diagnostic team. If you do not understand what is going on then the diagnosis most likely will be of less help to your child. You are the only one who is in for the duration. The others only have a brief contact with your child. You will be involved for the rest of your life.

Perhaps you disagree with the diagnosis. Before you make an appointment for another evaluation, identify which parts of the diagnosis strike you as wrong. Disagreeing may not change the diagnosis and if you can not be specific you may have to take your child to another clinic for a full set of evaluations. This is very expensive and can be very trying on you emotionally. If you obtain the same results after the second set of evaluations and you still disagree, stop before you go on to more expensive evaluations and ask yourself if you are expecting a certain diagnosis before the tests are even done. This is a very common expectation, but it could be very harmful to you and your family if you do not recognize it early. You have certain financial, physical and emotional limitations. Talk with friends or other parents of handicapped children about their experiences with diagnostic evaluations, they may be able to help you with your feelings. You may disagree vehemently with all the diagnoses. If your friends share your feelings, then organize yourselves to see what can be done to correct the situation.

The written statement you receive from the diagnosis will be very important for your child's future. If the diagnosis was a preliminary requirement to placement in a special school or a regular school, the statement of results will contain the information that the schools will use along with interviews and tests done at the school to place your child in a certain program. For your and your child's best interests you should start a file or account, if you have not already done so, of all the visits you have made and all the persons you have seen. In that way you will always have a permanent record for any future purposes. For example, if you move, sometimes the records are slow in following you to your new residence. This time lapse could hinder placement for your child as you get settled.

The diagnosis and its recommendation for placement open up a whole new area for your investigation — the schools.

Recommended for Further Reading

McNamara, Joan and Bernard. *The Special Child Handbook*. New York: Hawthorn
1977 Books.

A non-technical manual for parents of children who have special needs, based on personal and professional experience of the authors. This manual expands on every subject we have covered in our manual, giving more examples and information than we had room for. A very good book to have for your reference throughout your child's lifetime.

Commonly Seen Specialists

Medical Specialists	Area of Specialty
Cardiologist	Heart
Dermatologist	Skin
Endocrinologist	Ductless glands (such as adrenal, thyroid, pituitary)
Gastroenterologist	Stomach and intestines
Gynecologist	Women's reproductive organs
Hematologist	Blood
Neonatologist	Newborn children
Nephrologist	Kidneys
Neurologist	Nervous system and brain
Obstetrician	Pregnancy, labor and delivery
Oncologist	Tumors and aberrant growth
Ophthalmologist	Functions and diseases of the eye
Oral Surgeon	Surgery of the mouth
Orthodontist	Treatment of crooked teeth
Orthopedist	Surgery for deformities and diseases of bones, muscles and joints
Osteopath(ist)	Works with the neuro-musculoskeletal system
Otolaryngologist	Ear, nose and throat
Pediatrician	Children and childhood diseases
Plastic Surgeon	Skin grafts and cosmetic surgery
Psychiatrist	Treatment of diseases of the mind
Rheumatologist	Diseases of muscles, bones and nerves (arthritis, e.g.)
Urologist	Diseases of the urinary tract

Professionals Involved With Special Education

Schools and educational programs involve a wide variety of specialists. Too often parents have little idea of how these specialists work with their children and are uncertain about what questions to ask to obtain information. Since titles can be confusing, here is a brief description of the kinds of professionals who may have contact with your child in a special education setting. We have tried to indicate a few of the ways in which you could work with them to maximize the development of your child.

It is impossible to give an exact number to how many times you should contact a particular professional throughout the year. You will meet with them regularly at parent-teacher conferences, staffings, and other school-related meetings. All the professionals involved with your child should be willing to give individual advice and assistance when needed, but their primary job after all is to work with the children. They cannot be tied up on the telephone or in person with parents too much of the time or the children's education and therapy would suffer. As a rule-of-thumb then we would suggest that you try to talk individually to each important professional in your child's life once during each school year. If there are special needs or unusual circumstances, they might be able to assist upon three or four occasions in any one school year. If you need help more often than that, then you should probably seek assistance outside the school system. Therefore, as we discuss the professionals involved with special education, and suggest that you keep in "regular" contact with them, what we really mean is that you should try to approach each on an individual basis once a year.

The School Nurse

The nurse provides medical direction for all staff to fulfill the students' health needs. The nurse is concerned with the general health of your child, emotional as well as medical. You may be requested to provide a health history when your child is first enrolled. For the health history, you may be asked about such things as: medical problems of other family members, pregnancy and birth experiences, types of evaluations your child has had, developmental milestones (age at which your child first smiled, sat, crawled, stood, walked, was toilet trained), childhood illnesses, general behavior (eating, sleeping, playing, discipline), and whether you have any concerns about your child's health. Illinois State Law requires that every child have a complete record of up-to-date immunizations and a physical and dental examination upon entering school, at fifth grade or age 10, and 15 years of age. Starting with your child's own baby book, it is important that you, the parent, keep detailed accurate records and coordinate medical and dental records so the nurse can get complete information from you. You will be asked to sign a release of information for records from physicians and hospitals. Continue to keep records and update your child's school medical history. Acquaint yourself with the nurse even if there are no specific problems at the time.

If you have concerns about your child's medication or did not understand a medical diagnosis, the nurse can provide a fuller explanation. If you need information about what to do in the case of such things as a rash, dental hygiene, toileting, masturbation, or keeping a cast dry, the nurse can give you guidelines. If your child requires a special diet to promote physical or social development, you must work together to plan and follow menu guides. The nurse can help establish self care habits to promote good health and hygiene, including preparing young girls for the onset of menstruation and teaching children to administer their own medication.

If surgery is coming up for your child, the nurse can share the experiences of other parents (while keeping all names confidential) and help prepare your child for the hospital experience. After hospitalization the nurse can help you decide when your child is ready to return to school. If you are having trouble finding a pediatrician, dentist, or other specialist the nurse can provide the names of those who are used by other parents. On the other hand, it would help other parents if you would tell the nurse about good medical professionals you have encountered, so those names can be passed along to other parents who are searching, too. Residential facilities, such as Waukegan Developmental Center, have doctors contracted for regular medical examinations and care whose names would be made available to you upon request. If your child is in a residential facility, it is important to be available to accompany the nurse when it is necessary for your child to visit a specialist or clinic at another location.

Call the nurse if you are uncertain about anything relating to your child's general health or well-being. The nurse can provide the information or give you a referral.

The Social Worker

A social worker has a masters degree (M.S.W.) or a doctorate (D.S.W.) as certification of training in helping individuals cope more effectively with personal, family, school, and community relationships. You may be requested to provide a family history when your child is first enrolled. Family histories include such things as: your child's experiences in other schools and programs, your child's acceptance by others, your familiarity with other agencies in the community as sources of economic and emotional support, your child's level of functioning, particular interests and hobbies, and concerns about your child's capacity for development. Provide the social worker with information about your child's behavior and activities at home even if there are no specific problems at the time. Keep the social worker informed about changes in the home that might help your child's behavior as well as about those that might be emotionally upsetting.

If you are uncertain about what to expect for your child, the social worker can help you evaluate these typical concerns. For example, you may be concerned about whether your child will ever be self-supporting or what care will be needed and provided in the future. You may be concerned about the child's impact upon your marriage, rivalries with brothers and sisters for attention, social interactions with other families in your neighborhood, or about how to explain your child's disabilities to others. The social worker may encourage follow-up visits which include other family members, or volunteer to meet with a discussion group of parents who have expressed similar concerns. Sometimes the social worker may evaluate a child's level of functioning or provide play therapy for an individual child experiencing emotional or behavioral problems. The social worker acts as the connecting link between child, school, parents, and community. By attending community meetings, the social worker gains knowledge about other agencies that can help you with a particular financial or family need or in the event of an emergency. Most families experience financial problems at one time or another and the special needs of your child may create added expenses that aggravate these problems. The social worker can help you find services within your ability to pay. Their knowledge and experience can help you choose appropriate clothes for your child, or solve problems about jobs, housing, and transportation.

Some crises can be avoided through advance planning. The social worker can help you examine program and residential options, help you fill out application forms, and go along with you if you anticipate difficulty in dealing with an agency or professional. The social worker is the person to call if you have questions about relationships within your family or with others. The social worker will provide the information or help you in the search to find other sources.

The Psychologist

A psychologist has a masters degree (M.A. or M.Sc.) or a doctorate (Ph.D.) as certification of training in the study of individual development and human behavior. A psychologist may do testing, provide counseling services to students and family members, and work with other staff to design an appropriate learning program and classroom curriculum for each child. Before being admitted to a special education setting, your child will have received a psychological assessment to determine the most appropriate placement. The tests provide information about what your child knows (cognitive development) and can do (performance evaluation). When your child's results are compared to those for other children of the same age (norm-referenced measurement), this helps decide what would be the least restrictive educational setting for your child -- the one that will provide your child with the best opportunity to learn in a setting as similar to that for other children of the same age as possible.

When your child's test results are shared with teachers and other professionals, this helps decide where the educational and training process in the classroom should begin (criterion-referenced measurement). An individualized educational program (IEP) is developed to provide a specially designed education to meet the unique needs of your child. What the school expects your child to accomplish should be carefully spelled out. You should get in the habit of going over your child's test results and educational objectives carefully to make sure they accurately reflect what your child can do. Your observations of your child's behavior in the home provide an important check on the psychologists' record of your child's behavior and behavior change in the testing situation. Ask questions if you do not understand what the test results mean. Get copies for your own files.

Your most important job is to supplement the scores from the tests with information about your child as an individual. As a member of the team -- receiving and giving information, asking for and providing explanations -- your child's school progress will be smoother and have continuity. The psychologist can then become a valued consultant if your child's behavior or abilities change, if discipline becomes a problem for example, or if it seems a different educational program might be better for your child. Many psychologists also offer counseling to parents, children in the program, and other family members as well as being involved in curriculum planning.

The Speech/Language/Hearing Therapist

The therapist who works with your child on communication skills may be known by a variety of titles including all or some of the words "Speech," "Language" and "Hearing." This professional's training will have included a background in child development as well as in diagnosing delays in language development, abilities to communicate, and in designing remedial programs. A hearing test (audiogram), picture, and other tests will be given to determine your child's ability to understand gestures, pictures and spoken or printed words which are all symbols for the ideas or objects they represent. These are known as receptive functions. In addition tests will be given to determine your child's developmental level in expressive functions -- the ability to communicate with others through gestures, facial expressions, speech and/or writing in an appropriate way. An evaluation of your child's tongue, lips, jaws, respiration and swallowing may also be undertaken if speech sounds are different from our usual spoken language. As the parent you may be asked to contribute observational information about words or symbols your child understands, the meaning of certain gestures or speech sounds, the age at which your child began babbling and saying words, and the number of words your child knows (vocabulary).

Language activities will be structured according to your child's developmental level. By keeping in touch with the therapist on an on-going basis, you can help your child practice at home so that the communication skills being learned are generalized beyond the school setting. Knowing that your child has a developmental disability, it may be all too easy to slip into the pattern of anticipating wants and needs so your child does not consciously recognize and communicate them. This can lead to later frustration if others cannot intuitively respond as you have done. Learning and self-reliance can be promoted through reinforcement and support at home.

The Physical Therapist

The physical therapist has an undergraduate science degree (B.Sc.) with additional postgraduate work in a medical setting. Service is provided to physically or multiply handicapped students who require therapy to maintain or improve their physical condition. The law requires all physical therapy be done under the direction of a physician. Thus, it is important that you help the physical therapist obtain the necessary forms from your doctor. Since your child may have seen several doctors, you can best decide which doctor has the most contact with your child and will be best able to supervise therapy on an on-going basis.

The physical therapist works on gross motor skills (the use of large muscle groups) to increase physical functioning by preventing or correcting deformity and developing normal movement. Special attention is paid to developing independent movement -- touching, reaching, rolling, sitting, crawling, standing, walking, jumping, skipping, kicking, bouncing a ball and so on. Such activities provide children with greater mobility.

Physical therapists act as liaisons between the doctor, the school, and you as parents. If you do not understand a particular surgical procedure, they can explain it to you. They can make referrals to doctors, clinics or hospitals for particular physical problems since they maintain regular contact. They can also help you find suppliers if you need to obtain special equipment or have it fixed. They can recommend toys and activities which will utilize your child's physical abilities and talents. This can be especially helpful when you are buying gifts for special occasions such as a birthday. Engaging in appropriate activities can be fun, aid development, and avoid frustration.

Usually children are not present at conferences nor would there be time during a conference to go through your child's entire therapy program. Therefore, you could make an appointment to go in and observe your child in a therapy session. The physical therapist can explain what the activities are designed to accomplish and help you select out those which it would be possible to work on at home in the everyday course of events.

The Occupational Therapist

The occupational therapist has college training and clinical practice related to physiology (the body and how it functions) and treatment techniques for specific disabilities. The occupational therapist is concerned with the skills necessary for work and daily living, and will therefore focus more upon activities than upon specific exercises. For example, the ability to reach, grasp, hold, manipulate, and release is important for a broad range of activities from eating properly to coloring, cutting with scissors, drawing, and writing.

A training program will be based upon clearly defined tasks. For example, if training in dressing and undressing were undertaken the program would begin with simpler skills (getting a child to take off a hat, socks, or mittens and to cooperate in dressing by extending an arm or leg into the clothing). As the child accomplishes the simpler steps more complex tasks are undertaken (learning to use zippers, snaps and buttons). The occupational therapist can help you understand the sequential steps which have to be learned in order to accomplish tasks often taken for granted, tying your shoes, for example. The occupational therapist will break down this task into eight steps. You can also help your child to master each step before the next one is tried. Shoe tying is complex. It requires that the person:

1. Picks up one lace in left hand and other lace in right hand

2. Crosses left lace to right side of shoe and right lace to left side

3. Makes tunnel

4. Takes lace on left side placing it to left side of shoe

5. Takes end of both laces (one in each hand) and pulls in opposite direction

6. Makes a "rabbit ear" with each lace

7. Crosses left "ear" on top of right "ear," pushing behind and through "rabbit hole"

8. Pulls both laces securely in opposite directions.

Sometimes a particular disability may make it difficult to carry out simple activities, for example holding a pencil or spoon. The occupational therapist can suggest changes to existing equipment so that the level of independence can be increased. Craft activities, such as ceramics, weaving and woodworking, will be taught by breaking them down into smaller steps which become progressively more difficult. Again, such enjoyable activities can be carried over into the home if you know enough to neither make them too simple nor too complex.

Work and daily living activities will be learned much faster if you also work on them at home. Initially, it takes a much longer time to let your child do things alone at home. But, in the long run, your child will be much more independent, and you will actually be doing less because your child is doing more.

Activity Therapist/Recreation Director

An activity therapist is a job title used in state facilities to refer to all employees in recreation. In the community, the same job with a park district would be called a recreation director; in schools, the physical education teacher. Persons in these positions will have college training in physical education and recreation. In addition to working on gross and fine motor skills, the activity/recreation therapist teaches use of leisure time through appropriate socialization techniques.

A wide range of activities may be involved. Students may be taught to climb stairs, to walk up and down curbs, so they have more mobility in community settings. Then on a field trip they can climb the 50 stairs to the entrance of the Museum of Science and Industry, for example. Older and more capable students will be taught leisure skills for their evening and weekend hours, such as macrame, pocket billiards, and dancing. Be aware of the extent of your child's activities and events at school in order to incorporate your child's new skills into family activities.

Children can learn as much through games and things that are fun as they can in a classroom setting. Even a simple game such as bouncing a ball can be used to teach numbers by counting the number of bounces, to teach coordination by introducing a target, and to build group skills.

Whether performing or listening, music can be educational as well as enjoyable entertainment. Teaching rhythm can be used to reinforce counting skills. Attending concerts (outside as well as inside) can expand your child's social world.

Many events that the activity/recreation therapist plans, can include families and friends. Student plays and programs can provide a sense of accomplishment for doing something special. Summer camps, overnights, style shows and Special Olympics give the developmentally disabled child recognition and self-confidence, and allow families to participate.

Activities learned with the activities/recreation therapist can best be incorporated into family activities if performance expectations are consistent. For example, a swimming program can involve everything from enjoying the water to deep water swimming. If your child is learning to float, expecting him or her to swim would be unrealistic.

Vocational Counselors

Pre-vocational and vocational evaluators, teachers, and counselors will have a college background in special education, usually combined with industrial or workshop experience. Instructional staff working in this area view school as the stepping stone to employment. They focus on developing job skills and positive work attitudes. This philosophy may be implemented within the curriculum at any age — for preschoolers as well as adolescents and adults -- but will vary from school to school. Services provided can include realistic training programs both within the school and the community.

Each student's vocational strengths and weaknesses are assessed through the use of work samples. The samples are taken as students perform jobs within a supervised environment which is a close approximation of work settings in the community. Tasks vary in complexity: collating, sorting, counting, packaging, mailing, labeling, stamping, use of hand and power tools, assembly line productions, custodial work, clerical work, food service, laundry, and yard work. Your input can be extremely valuable at this stage in helping the vocational staff to recognize and develop your child's special interests and areas of expertise. This is where the hobbies and interests developed at home can have a high pay-off. For example, if your child has observed and helped with home maintenance repairs this would be helpful in obtaining employment in the building trades or light industry.

Similarly, work habits and attitudes are learned over the years as children observe and work with their parents. Prevocational and vocational training will be most effective if the groundwork has been laid and is maintained at home. Positive work habits and attitudes include punctuality, following directions, getting along with supervisors and co-workers, and persisting at a task until it is completed.

The Classroom Teacher

In one way the classroom teacher is the professional most familiar to you because of your own educational background. But the special education teacher will most likely be different than the teachers you had in some important ways. Special education teachers treat each child individually by developing separate lesson plans and goals. Each child in a classroom can be working with different materials. Each child will be evaluated in terms of his or her own progress. There are no classroom tests. Children are not in competition with each other. Although abilities obviously differ, each and every child experiences success.

Another thing that will probably be quite different is the appearance of the classroom. Your child may not even sit at a desk, or do so for only short periods of time. The rooms are subdivided into work areas by moveable cupboards and partitions. Art materials and games, as well as books, can be used for instructional purposes. Although the room may not look as seriously academic as your classrooms did, the way it is set up has an educational purpose. Each teacher sets up his or her own room to best meet the needs of the students. You will want to talk to your child's teacher to understand the setting and activities. You may be able to incorporate some of these ideas into your own home.

The following account of how one teacher arranged her room provides an insight into the special education philosophy:

My classroom is definitely arranged and set up for the children's benefit. I want them to experiment with all the different things we have in the room. I want them to initiate these experiments. Therefore, I believe things must be within their reach. In addition, I want them to learn that there are limits, and that there are things that they may not touch. I think this helps develop their self-control and self-discipline.

I want the children to develop better self-confidence. This is why four out of six bulletin boards are designed particularly for the children. Since each child has an area in which success is experienced, I have tried to provide a place for each area to be represented. The children really enjoy seeing their work on display, as well as seeing their friends' work on display.

I believe strongly in teaching children how to care for their possessions, as well as possessions that belong to the class. The weekly job chart is designed to teach them certain responsibilities (watering plants, straightening shelves, inspecting the desks for neatness twice a week, changing the bulletin boards, being teacher's assistant or cooking assistant, and reading the class a story at the end of the day).

My room is divided into four main areas. The first area is the center of the room, which contains four rows of desks, with three desks in each row. The only exception is that I have one child's desk in an isolated area away from the group because his behavior is extremely disruptive to the other children. The next major area in my room contains three large tables with chairs. These tables are used for drawing, completing work or playing board games. The third major area of my room consists of three plastic cushions, and one large cotton pillow. These cushions are located under the windows in the classroom. The final area is a little room, completely private, built into the corner of the classroom. This room is used for "time-out" for bad behavior, for privacy, or for reading groups.

The Principal and Other Administrators

The principal of a school, director of a private facility, superintendent of a state facility, and other types of administrators are responsible for, among other tasks, setting the general philosophy for the entire facility, hiring all staff, setting the budget, coordinating instructional and therapeutic programs, and representing the facility in the community. They usually have postgraduate training in addition to years of experience in the field. Ultimately they structure the overall curriculum, provide the framework within which activities are conducted, and handle both day-to-day management and long-range planning.

The extent to which administrators are actually involved with individual children and families depends upon the size of the facility. All would be actively involved with parent organizations. They are always available for staffings and parent-teacher conferences although they would not necessarily routinely attend. They are responsible for ensuring that the facility as a whole runs as smoothly as possible within the limitations set by policy boards and government regulations.

Since developmentally disabled children may be in the same school or program for several years, you will develop an understanding of how your child progresses within the facility. If you have ideas or questions about your child's progression within or between facilities, then you should talk to the principal/director/superintendent. They should be able to help you assess present achievements in the light of future life-cycle planning. The key question is -- education for what? Is the education provided preparing your child for maximum independence upon graduation? Planning which transcends the individual classroom is always an administrative decision.

Administrative and Auxiliary Staff

In the course of your child's everyday activities, there is a great deal of contact with other personnel. Every person in the facility -- such as secretaries, custodians, aides, bus drivers, librarians, cooks -- is involved in the education of your child. Each provides your child with insights into different job opportunities and the wider community. With in-service training at the school your child may be working directly with or for these people. A special greeting or word of thanks would be appreciated because their tremendous contribution is often overlooked.

Your child's interaction with the school bus or van driver can set the tone for the entire day or field trip. The experience will be better if your child behaves well. You can reinforce appropriate behavior by taking your child for rides in the car or on public transportation. Teach them the importance of keeping a seat belt fastened. Insist that your children do not litter. If your child is ready and waiting for the bus in a happy frame of mind, the bus driver's job is easier and your child's experience more pleasant.

Residential and classroom aides could often make considerably more money checking out groceries or working in a factory, restaurant or hospital. They choose to work with developmentally disabled children, which is both physically and emotionally difficult.

The following comments from some staff about their interactions with parents provide an insight into how you can be appreciative and supportive of their efforts, thereby creating a positive environment for your child.

I think my biggest complaint goes to the parents who come in and never have a nice thing to say. They just come to their child's room and start complaining. One day I tried my hardest to have one of the children perfect for her parents. I had a pretty little dress on her and I had her hair parted in the middle with little barrets on each side. I had shoes and pretty white lace socks on her and she had a clean face. I had made sure all her toys were on her bed and I put a blanket on her bed to make it look like a bedspread. The minute this child's parents came in they complained because her hair was combed wrong. All day I fixed things up for this one child and is that all they can say?

For most people the job goes beyond the hours they work. It's the volunteering, the field trips, the children we take out for the day, and the special little things you buy for a child who needs just a little extra love and attention. There is never enough time for everyone and this is where the parents are needed. When we work together all this must make a child feel doubly loved.

One thing I think parents fail to realize is that their child is with many others, all greatly needing attention. I work hard to carry out the directives from parents which are good, but I hurt for those children whose parents are not involved and try to find extra time to do the same things. Is it the children's fault that their parents don't come?

I like parents who treat their child on his own level - if he's pretty normal intellectually but doesn't present that normal an appearance, and the parents talk to him on a normal level, it's terrific. They're telling him he's not letting them down; they're not thinking of him as an eternal baby but giving him credit for what he is and where he is in his own life.

I like something I've seen some parents do - let "you" and "me" become "we."

I don't like it when parents make a staff member feel attacked on a personal level. Even if staff understand on an intellectual level what parents are going through, on an emotional level staff are still people with feelings of their own.

If they have a complaint they should try to see if it is really our negligence or their own hardship in accepting their child's problems. If the latter is the case, rather than saying something in anger about the child having on the wrong clothes, share with us their frustrations because he cannot dress himself.

Willingness to understand that those who care for their children are human and fallible, and all will not always be perfect.

I expect parents to sometimes have really sad or uptight days. But I also expect them to face the fact that these feelings exist and color their reactions. We cry too, sometimes, and hurt so badly for their children and for them as their parents, too. If they're having a bad day, we'd like to share it and maybe take some of the load.

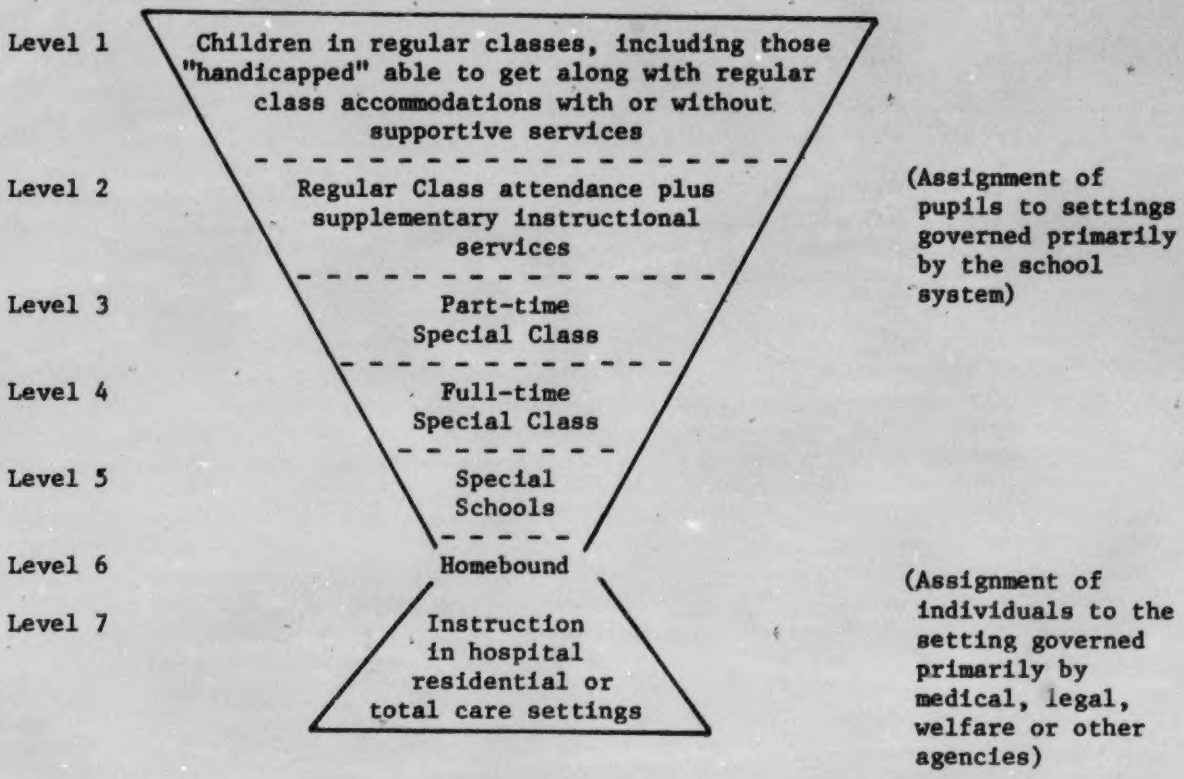
I like it when parents encourage their child's growth and development and encourage us to encourage their child's growth and development.

Education for the Developmentally Disabled

Special education for the developmentally disabled is available, by law, for all children needing these services from ages three to twenty-one. Private and public agencies also offer special education to the 0 - 3 population in early intervention programs.

The range of services offered is broad. Special education varies from supportive services (for example, resource rooms) offered in regular classes to instruction in hospitals, residential or total care settings. The following diagram shows the range of settings in which special education is provided.

The Council for Exceptional Children's (CEC)
Cascade System of
Special Education Service


Level 1
Children in regular classes, including those "handicapped" able to get along with regular class accommodations with or without supportive services
Level 2
Regular Class attendance plus supplementary instructional services
Level 3
Part-time Special Class
Level 4
Full-time Special Class
Level 5
Special Schools
Level 6
Homebound
Level 7
Instruction in hospital residential or total care settings
(Assignment of pupils to settings governed primarily by the school system)
(Assignment of individuals to the setting governed primarily by medical, legal, welfare or other agencies)

The tapered design is used in the chart to indicate the considerable difference in the numbers of children likely to be involved at the different levels of service. The most specialized facilities are likely to be needed by the fewest children. This conceptualization may be applied to organization of special educational services for children with various kinds of special needs.

Children move between the different levels of special education as their needs and abilities change. Children can be diagnosed at different ages. The more severely handicapped children are usually identified earlier than those children who have needs that are only recognized when they are in the school environment.

To inform you of the goals of special education, this chapter is set up to discuss special education services by age level, religious education, and preparation for adulthood. This chapter can only give you a broad understanding of the activities, objectives and services offered. For more specific information, consult with the special education districts listed in the directory. Although your child attends a school that serves your area of residence, you may find it helpful to visit other programs in Lake County, McHenry County, and northern Cook County so that you can understand the variety of curricula and activities that are offered to children with the same needs in different school districts.

Early Intervention

Early intervention programs provide the earliest possible educational treatment to young children who are developmentally disabled or who have developmental delays. The treatment begins by helping the family cope with the disability by stimulating development which helps to reduce the extent of the delays and may eliminate some. Children participate between birth and 3 years.

Early intervention programs vary in terms of their general and specific objectives. In a study of 25 early intervention programs in northern Illinois (including the Lake-McHenry Regional Program) Karen Vroegh of the Illinois Department of Mental Health and Developmental Disabilities' Institute for Juvenile Research identified some common general objectives. General objectives were to: provide services for developmentally delayed and/or potentially developmentally disabled children; provide stimulation for development; attempt to develop appropriate behaviors and self-help skills; prevent or alleviate retardation and developmental difficulties; and develop each child's maximum potential for the least restrictive placement at age three. Other objectives were: direct and train parents to carry out therapy for their children; educate parents about developmentally delayed children and child development; develop individualized education programs for each child; provide parent counseling; and socialize the developmentally delayed child.

The services provided by an early intervention program may include some or all of the following: referral, parent meetings, speech and language therapy, physical therapy, occupational therapy, education of the child, psychological evaluation, home visits, professional consultation, diagnostics, social case work, and baby-sitting and/or day care. Each early intervention program will offer a different core of services. Hopefully, you will be able to get the services you need at the early intervention program closest to where you live. If not, some programs can provide services outside their geographic area.

The number of hours your child is involved in an early intervention program will vary with the diagnosis and the kinds of delays your child has. Although quantity does not indicate quality, too little time (one hour per week or less) is probably not sufficient time to expect many changes unless you put in a lot of additional time and effort working at home. On the other hand, too much time (20 hours per week or more) may be too taxing and therefore not productive for a very young child. In Dr. Vroegh's study, five hours per week was the average amount of time children were involved in an early intervention program.

Early intervention services are offered at a facility or in your own home. Traveling to a facility can provide you with the opportunity to meet with other parents and children, to take advantage of better services and equipment available, and to have some relief from full-time child care. On the other hand, regular or occasional home visits provide a natural environment to practice skills in the course of your everyday activities, a convenience and savings on transportation costs and services if your child is too young or unable to go to a medical facility.

While goals cannot be guaranteed, you should be given some reasonable expectations as to what might be accomplished as a result of your participation. Discuss with the professionals what your child is able to do at home. You have the most extensive knowledge about your child. You should be involved in deciding which activities can be done at home. That is, you should be involved in the planning of the program for your child. For example, if you expect your child to develop in motor abilities, such as crawling, sitting and walking, then you should be involved in planning a program to accomplish these goals. Other goals you have might include learning the things your child should be able to do, helping your child learn to talk, helping your child become more independent, and sharing your experiences with other parents.

As you are involved with planning your child's program, you will receive verbal and written instructions from the professional staff. If you do not understand these instructions, you should ask the professionals to demonstrate what they mean by actually working with your child while you are present. Take notes as you are given instructions and demonstrations to help you remember what is to be done and why.

Scheduling and attending the therapy sessions will take time, effort and money. However, you will notice that your efforts are worthwhile. Some of the benefits to expect are: understanding your child better, knowing how to help your child, accepting your child's limitations more easily, finding your child easier to work with, having a sense of purpose, and expecting and receiving more from your child.

As you participate in the early intervention program and work with your child at home, you should keep records about your child's physical, social, emotional, mental, language and self-help progress. By keeping notes you will be more observant of changes as they occur and able to draw these changes to the attention of the program's professionals. On days when you get discouraged you will be able to read back through these notes and remember the areas where progress has occurred. Expect plateaus to occur (when there will be no progress for a period of time) and that on some occasions your child may not be able to do things he or she was able to do previously. Development proceeds unevenly. By keeping track of progress in all areas you will be able to focus on strengths and abilities instead of being discouraged by setbacks.

In addition to your personal record keeping you should receive progress reports from the early intervention program. These reports may be informal when you pick up your child or while you are watching or participating in a session. Meetings may be scheduled in a more formal way to discuss your child's developmental status and needs. The frequency of reporting will vary. You can encourage frequent feedback by asking questions, providing information about progress at home, and by making yourself available. Try not to schedule appointments so that you are always in a rush. There are no formal reporting requirements, but it would seem reasonable to expect written reports once or twice a year.

Keep the written reports and your notes so that when your child is placed in a preschool or special education program you can better inform the teacher about what to expect.

Preschool/Primary

Preschool education of children with developmental delays and disabilities is available from a variety of programs. Children who have developmental disabilities which are identifiable by the age of three, for example moderate mental retardation and some kinds of cerebral palsy, are eligible for special education services provided by the public school district. Children with developmental delays may be eligible for public school special education services and could also take advantage of other preschool programs which include children with handicapping conditions.

If your child has been in an early intervention program, the staff and other parents will have helped you select the appropriate preschool program for your child. Otherwise, you should contact the school district, which provides diagnostic and assessment services to determine your child's abilities and needs. The results of your child's diagnosis and assessment will determine whether he or she is eligible for public school services. While some school districts may inform you about other preschool programs serving some handicapped children, such as Head Start or Montessori, you will also want to contact those preschool programs. Whether or not your child is eligible for public school special education services you might find that your child could benefit from a regular preschool experience. Some children attend both.

In addition to preschool screening clinics, you could check with the following for listings of local preschool and day care programs: Department of Welfare, Department of Children and Family Services, County Health Department, and the yellow pages of the telephone directory under "Day Care" and "Nursery Schools." There are two forms of preschool experiences available to your child, home-based and center-based. The choice between these is based on your own preferences and needs. Some parents prefer that their children remain in a home environment until they reach primary school age; others, a more structured, school-like environment. Your best bet is to visit a number of child care homes and centers before you make your final decision. You can save time if you telephone before you visit to make certain the program will meet your needs regarding the hours of the day and the days of the week you need child care, and the age and developmental abilities of your child.

In deciding whether to enroll your child or not, these are some danger signals to watch for. For example, if you are discouraged from visiting the program, then you should rule out a center or home from your final choice. The director or teachers should be able to answer specific questions about what your child will do during the day. No child should be left without guidance for thirty minutes or more. The teacher or caregiver should look at the children when talking to them and give the general impression of caring about them.

During your child's preschool and primary school years, the education received will only be as good as the teachers who are providing the instruction and arranging your child's environment. A competent teacher should be:

Warm and responsive with children -- encourage children to turn to her or him for help and information, spend most of the time working with the children rather than arranging materials or talking with other adults;

Encouraging of intellectual growth and development -- guide children in using toys and materials, encourage decision-making by the children, have a set routine or schedule organized for the children that you think is appropriate, and ask questions that require creative, thoughtful, or imaginative answers; and

Respectful of the child's individual needs — make available pictures, photographs and books that reflect the ethnic and cultural backgrounds of all the children in the class, meet the special needs of your child, and be consistent in giving rewards and discipline.

The educational objective at the preschool and primary levels is to provide a setting within which the individual student can progress at his or her own rate. Educational programs are tailored to meet individuals' needs. Initially, instruction will be designed to assist children in the mastery of developmental tasks, such as the following:

Language -- understanding sounds as words, identification of familiar objects when named, using dolls and toys to express language ideas through play;

Visual - Motor Skills -- coordinating hand and eye movement, manipulating toys and tools, fingerpainting, using play dough, stringing beads, putting objects in containers, learning to use scissors, using crayons, and tracing lines;

Gross Motor Skills -- hopping, jumping, climbing stairs, bouncing and throwing a ball, swimming, and riding wheeled toys;

Visual Perceptual Areas -- sorting objects by color, size, shape and kind, matching objects with pictures of those objects, doing jigsaw puzzles, and reproducing patterns with pegboards, beads, and blocks;

Conceptual Skills -- learning colors, numbers, letters, first and last name, shapes, body parts, making up a story from pictures, playing pretend games, building models and creating pictures from clay, paint and crayons;

Social Skills -- dressing and undressing, toileting, listening to instructions, good table manners, participating in group games, working independently, and obeying rules.

As children gain some mastery over these developmental tasks, instruction will become more academically and vocationally oriented. For example, your child will begin to do schoolwork that is similar to your school experiences and that of your other children: mathematics, reading and writing, social studies, science, health, physical education, music and the arts. Within the classroom emphasis will be placed on learning centers, interest centers, and instructional areas for small groups. Your child will have an appropriate set of academic materials along with individual work assignments which will be checked regularly. Your child will learn to take pride in work done well. Within the classroom this will be accomplished by having bulletin boards displaying good papers or artwork. The special events and holidays celebrated, often including photographs of class activities, provide a positive sense of group identity.

Schools try to incorporate parents into their children's classroom activities by sending examples of work home with the children. By the age of three years, children have already learned whether their parents care about what they do or not. Some children carefully carry their work home, others discard it before they leave. It makes a difference. Children learn better and enjoy school more if parents reinforce what they are learning by taking an interest. Share in your children's accomplishments. Talk with them after school. Display their work in a prominent place at home, with magnets on the refrigerator door or on a bulletin board for example.

Whether or not you think a public or a private school offers the most appropriate educational setting for your child, the local school is the first point of contact for special education placement. Only after an evaluation by the local public school can a private school (such as Grove) accept a child.

Secondary

As children grow up, persons in the community expect behaviors and acts to coincide with age and size. Behaviors which are considered "cute" when children are small are inappropriate for older children. Strange mannerisms may be attention-getting devices, the result of improper rewards for "cute" behavior, and quite unnecessary. The more ingrained they are, the more difficult it will be to eliminate them. For that reason it is important to begin to provide a proper foundation for age-appropriate social behaviors. An example from To Give An Edge, a handbook for parents of Down's Syndrome children is as follows (see the Chapter on Mental Retardation for the complete reference on this publication):

> A group of young retarded persons came to my home one night after a band concert for cokes and a snack. One young man spent the entire evening opening closet and cupboard doors looking for my "white pipe" (dryer vent) and any other appliances I might have. His interest in mechanical objects was admirable, but his behavior as a guest in my home was deplorable. Even more deplorable was the fact that his chaperones (teachers from his school) thought his behavior funny and laughed at him.

The development of proper behavior is a process which begins when a child is young. Parents teach their children appropriate behaviors and make sure the children conform to their expectations. As the child becomes an adolescent he or she begins to assume responsibility. For example, if an eight year old child is dressed inappropriately the parent is held responsible, not the child. However, a teenager who dresses inappropriately is blamed, laughed at or ridiculed.

The process of assuming responsibility for self-care, (such as proper grooming, clothes buying and maintenance, and food purchase and preparation) mobility (using public transportation or bicycle to get around) and self-discipline (recognizing limits to freedom and sense of adult responsibility) takes a long time. Parents should meet with school professionals to discuss the best ways to help their child learn the responsibility of adulthood. Expectations and experiences should be consistent between home and school.

School curricula begin emphasizing these skills before the developmentally disabled child reaches adolescence. Self-care skills, mobility training and self-discipline will have been introduced during the primary school years. When they have been mastered in the classroom, they can be practiced in the community. Students who have learned to use the school's laundry facilities can then, with supervision, try to use a community laundromat. Opening and using bank accounts, planning trips to the grocery store, selecting appropriate foods and making the correct change are some examples of possible activities in the community in which secondary classes might engage. The community becomes a classroom where your child can practice independent skills and appropriate behaviors with the supervision of trained school personnel and volunteers.

The ventures into the community classroom are made only with careful preparation at school. Instruction involves the practical application of academic and self-help skills. Mathematics is used to purchase items, keep track of time, and measure lumber for woodworking activities. Language, reading and writing skills are used to recognize public signs (washrooms, traffic signs, buildings), to follow directions (preparing meals, doing a craft project, completing academic assignments), to read a newspaper, and to fill out a job application. Self-care and social skills are practiced at parties and dances as well as in the everyday course of events. Physical education leads to participation in group activities such as scouting, camping, skating, and swimming. Music, arts and crafts provide an option for working at hobbies in leisure time. As an adolescent, your child will be especially concerned about being like all the "other kids." In attempts to please peers, there may be a possibility that your child could be taken advantage of by those "other kids." This situation can be greatly minimized if your adolescent is comfortable with friends of both sexes, and has enough interests and friends to occupy his or her time and energy.

Answer questions about maturation in a straightforward, factual manner with as much detail as you think your child can understand. Girls need to be told about menstruation, that it is normal and recurring, and taught the necessary hygenic practices. Both boys and girls need an understanding of what becoming an adolescent is going to mean to them, how this process will affect their bodies and their relationships. Such instruction is usually included in home living or health and personal development classes. The instructor as well as the school nurse would be able to help if you need direction.

Physical and emotional changes are going to occur during adolescence though the age at which they occur varies. The extent and content of the discussions surrounding puberty will also vary depending on the nature of the disability and on the degree of comprehension of each individual adolescent. While discussions about puberty should be undertaken with an attitude as natural as possible, dwelling on the sexual aspects of adolescence may, in some children, provoke an undue curiosity about sex. But if these ongoing conversations can be combined with a learning about social interactions (how to talk with members of the opposite sex, what to do on a date, how to get involved in activities like athletics, dramatics, writing) then the curiosity about sex tends to be put into its proper perspective: one normal aspect of growing up.

None of this is easy for adolescents, teachers or parents. This turmoil is as puzzling for adolescents as it is for adults. Adolescents are optimistic about approaching adulthood and feel a new sense of power with their increased size. They must be taught to appreciate the responsibilities that accompany independence. They need freedom, but must first have learned to make decisions and behave appropriately. Teachers, administrators and parents can assist by setting consistent limits.

As you help your child towards becoming as self-reliant as possible, there are many small changes that will smooth the transition. Your child's environment should be restructured to be age-appropriate. Toys, games, music and the way your child's room is decorated should reflect teen-age interests (entertainers, automobiles, space exploration, science fiction, travel). Personal appearance can facilitate or hinder community acceptance (hair style, glasses, dental work, make-up). Personal appearance and room decor are areas where there should be sensitivity to what is age-appropriate rather than remaining with what is developmentally appropriate. "Childish" styles and nursery rhyme motifs are not appropriate for adolescents, but their appreciation for color and beauty can still be maintained. Peers at school and others in the community will more readily accept a person who looks and acts like everyone else, than one who does not.

Transitional

By their senior year in high school, some students will be out in the community with a job placement. If the student is successful, the school will encourage graduation and the commencement of full-time work. Legally, students can remain in special education until the age of 21, but once they have received their diplomas they are no longer eligible. If the job does not work out and there is no immediate prospect of another, the person who has accepted the diploma cannot return to school. A diploma with inadequate job training is quite worthless. Your child should only graduate after the senior year of high school if you are certain that the extra training would not be beneficial. Should you disagree with the school on the timing of your child's graduation, you may appeal (see chapter on "Parents as Legal and Legislative Advocates").

During the transitional stage of special education, the focus of your child's instruction should be the refinement of social, vocational and independent living skills geared towards your child's future work and living capabilities. Students who will later live in supported living arrangements, community living facilities, or other community placements should become familiar with the routines, responsibilities and expectations that those facilities demand. Students working part-time jobs should get used to longer working hours, refine job hunting skills, and work on appropriate employment behavior. Social activities should be more community-based rather than school-provided. Groups of friends can go to sports events, movies, and other entertainment; participate in recreation sponsored by community agencies and facilities, and continue to entertain others in their homes with parties and informal get-togethers. School instruction and guidance on these skills should be reinforced at home. Together, school and parents can make the transition from school to work and from home to community living much smoother.

It is the usual course of events for a young woman or man to leave home upon reaching adulthood. For the developmentally disabled there is a need to establish independence appropriate to skill level and competency. Options are available to developmentally disabled adults for community and residential living.

Religious Education

In addition to the religious training you may be giving your child at home, churches and synagogues in Lake County are beginning to take a real interest in the religious education of handicapped children. Several of them have well-established special religious education classes that try to instill in their special members a sense of the tradition and rituals of their particular faith.

The most highly organized system of religious education is the Special Religious Education (SPRED) organization instituted by the Roman Catholic Archdiocese of Chicago in 1961. Catholic church parishes sponsor religious education classes for all levels of handicapped children. Church members volunteer to run the program which centers on a bi-weekly service for the children. All volunteers for the program receive training at the Chicago offices of SPRED, which requires a considerable commitment for those who wish to be teachers and assistants. Three age groups of children (6-11, 11-16, and 17-21) take part in a session which might happen according to the following plan. At the beginning of each session there is a forty-five minute activity where each child interacts individually with the staff doing developmental activities based on the theories of Maria Montessori. A quieting time follows and then the group moves to a second room where an altar with candles, bible, and soft music are ready for the service. The leader gives a lesson to the group and a singing session follows. Afterwards, a small party, or celebration, is held with food and beverages. Several Catholic churches in Lake County already have a SPRED program in operation or in conjunction with other Catholic parishes. If your parish does not have a SPRED program and you are interested in starting one, talk to your parish pastor or talk to someone at the SPRED offices in Chicago. They will gladly send you some pamphlets and brochures on how to start a SPRED program in your parish.

Synagogues in Lake County have begun to serve Jewish children with handicaps. They focus exclusively on the higher functioning children (those with learning disabilities) ages eight to thirteen. Within a few years the Board of Jewish Education in Chicago hopes the programs can expand to include children who function in the moderate range. They hope to start classes for handicapped adolescents, too. Religious education consists of learning about holidays, customs and history in preparation for the child's Bar or Bat Mitzvah. Charges for the special religious education programs are the same as, or slightly higher than, the charges for regular religious education programs because teachers usually have public school special education certification. If your synagogue does not have a special program for your child, talk to the synagogue's educational director or contact the Board of Jewish Education.

Some Protestant churches in Lake County have their own special religious education programs started by church members who saw the need for involving everyone in their communities. The types of instruction differ with each church. If your church does not offer such a program, talk to your minister or try to get together with other parishioners who may have a special child like yours and see what kind of religious education program you can set up. Other churches that already have programs may be able to assist you in developing one yourself.

A great asset is the Waukegan Developmental Center. It has a full-time resident chaplain who has coordinated many different types of services for the residents at the center. Catholic, Jewish, Protestant and non-denominational services are held on the campus. The chaplain has opened the door for community members in all of Lake County to attend the services and take part in religious education programs held during the week. For more information, check the back of the manual for specific programs.

Developmentally disabled children should have the same opportunities to participate in religious services and religious education as other children do. If your church or synagogue does not provide special religious education, you may be able to organize classes for children with handicaps by contacting interested members of your church community.

Education for What?

Your child can be expected to live a fulfilling, independent life as an adult with appropriate supervision if you have put life-course planning into effect. So much depends on the attitudes and expectations of parents. Subjects taught in classrooms gain reality through family acceptance and reinforcement. This Chapter has been organized to help you think ahead at the same time you are dealing with the concrete realities of the here and now. The following checklist may further help you gauge your child's present abilities and provide a guide for future planning.

Life Course Planning Checklist

Is appropriately dressed; carries self well; appears in good health; is personally clean and wholesome-looking; does not call undue attention to self socially.

Can prepare own lunch; knows how to sew on a missing button or mend a small hole, shines shoes; keeps self well-groomed.

Takes care of own room, including making the bed, setting out clothes for the next day.

Sets alarm clock properly, gets up on time, keeps dates.

Uses leisure time appropriately; is interested in sports or hobbies or the arts.

Knows he or she is different; accepts limitations; is able to either compensate or fully utilize potentials.

Assists in any or all of these: dishwashing, table setting, table clean-up, lawn care, snow shoveling, garbage disposal, watering plants, feeding pets, replacing light bulbs, answering doorbell.

Takes part in school activities such as sports, class newspaper, glee club, band, other clubs.

Handles responsibilities such as giving out and collecting school assignments; acts as messenger and monitor; runs small errands; assists in room clean up; handles bulletin board.

Has good health habits; good eating and sleeping habits; knows how to call if sick; observes safety precautions; has good attendance and punctuality records.

Can use hand-machine tools; uses electric or gas stove; keeps work areas clean; completes projects on time; follows instructions; asks for help when needed; helps others.

Goes to neighborhood stores, purchases either food or personal items, comes back on time with proper items and correct change.

Can travel independently to the following: church or synagogue, friends' homes, movies, parks, post office, restaurants, library, museums, employment office, rehabilitation office, bank, doctor's office, dentist's office, barber or beauty shop.

Handles money for personal shopping; knows what a check is; keeps bank account; budgets properly; uses coin-operated telephone and washer-dryers.

Carries on appropriate conversation with friends; engages in normal family discussions.

Writes legibly; can write own letter; can fill out job applications; knows social security number; makes bank deposits and withdrawals.

Writes name, address and telephone number with either pen or pencil.

Correctly dials the telephone; can call friends and relatives.

Reads newspapers; want ads; uses cook book; handles street directories; uses phone book; knows street and bus signs; recognizes safety signals.

Follows up on newspaper want ads, calls or writes for job interviews, handles her/ himself satisfactorily on the interviews.

Understands the relations between work and pay; can plan life accordingly, with safeguards to protect earnings and job.

Sees self as a young adult, able to assume adult responsibilities in competitive job.

If necessary, can make use of available social welfare agencies, if in need of post-school help due to loss of job or personal problems.

Vocational Services

With the trend away from large institutions and towards community involvement, the question of what your child will do upon leaving school becomes critical. If you have been fortunate, the school your child attended will have provided vocational training, on-the-job work experience and prepared your child for full-time employment upon graduation. On the other hand, all of these steps may not have been completed. It may be necessary for you to get involved. It is not in the best interests of you or your child, for your child simply to stay at home after graduation.

The Meaning of Work

Early adulthood provides just as much opportunity for developing new skills as does any other age level. The desire to grow up is deeply rooted in our society. The most convincing symbol of growing up is the ability to earn money, not necessarily the ability to be economically self-supporting.

A job is one of the most important ways in which we define ourselves. We evaluate our worth to society and to ourselves in terms of what we do and the quality of our performance. Lifework means much more than simply earning a living. Having a job is the mechanism whereby one participates in the life of the community. Having a job provides a structure for one's day. There is a definite time for work, therefore, a definite time for meals and leisure. We structure our weeks, months, and years around weekends, holidays and vacations. Having a job provides the opportunity for development of friendships with co-workers which often extend beyond the workplace. Some of the friendships develop into closer ties which provide companionship for other social activities. Recreation (team sports), special events (Christmas parties) and social activities (picnics) are often planned by and for co-workers. Work fulfills the same function of group membership as schools provide at an earlier age. The difference is that there is a transition from the age-graded environment of the school to a work-performance graded environment.

Alternative Places of Work

Day training programs for developmentally disabled adults serve primarily those profoundly/severely retarded and multiply handicapped individuals whose disabilities preclude placement in a Work Activity Program. The program provides a continuation of a day training program with emphasis on socialization, self-care, communication and preparation for participation in work activities. The objectives of the program include a strong emphasis on pre-vocational skill training.

A "work activities center shall mean a workshop or separate department of a workshop having an identifiable program, separate supervision and records, planned and designed exclusively to provide therapeutic activities including custodial activities -- and any purposeful activities so long as work or production is not the main purpose.,." (Fair Labor Standards Amendments of 1966: Public Law 89-601.). The primary target population for work activity programs are the severely and moderately developmentally disabled adults. Work Activity Programs should provide: evaluation, personal adjustment training, transportation, counseling and work activities. The goal is preparation for participation in a workshop.

"A sheltered workshop or workshop means a charitable organization or institution conducted not-for-profit but for the purpose of carrying out a recognized program of rehabilitation for handicapped workers, and/or providing such individuals with remunerative employment or other occupational rehabilitating activity of an educational or therapeutic nature" (Fair Labor Standards Amendments of 1966: Public Law 89-601).

A sheltered workshop program may consist of intermediate training experiences and/or extended work opportunities. Adults and adolescents are included who have either some past employment history, are work oriented, demonstrate potential to learn vocational skills, or require work-related activities to maintain their community functioning. Such persons may live either independently or in long-term care facilities, and may be active in other programs as well. Persons handicapped by emotional disturbance, mental illness, alcoholism or developmental disabilities can be programmed together so long as program activities are appropriate to meet the needs of the client.

Sheltered workshops provide both transitional workshop services for persons with potential for gainful employment and independent living and long-term employment for persons capable of working in a sheltered environment. The range of services should be comprehensive and include vocational evaluation--testing, training, counseling and placement; training in social, personal, health, work, and community-coping habits and skills; and job placement and follow-up services.

Developmentally disabled adults are performing hundreds of kinds of jobs in regular, competitive job settings. The following list may provide you with some ideas if your child is seeking work in the community or if your future goals include preparing your child for this eventuality.

Stock clerk
Dishwasher
Vegetable peeler
Landscape laborer
Elevator operator
Concession attendant
Sewing machine operator
Housemaid
Sales clerk
Mail handler
Farmhand
Assembly worker
Supermarket checkout clerk
Factory worker
Seamstress
Kick press operator
Truck loader
Baker's helper
Playground attendant
Clerk-typist
Egg collector
Freight handler
Mimeograph operator
Mother's helper
Painter's helper
Laboratory helper
Bottle washer
Nurse's aide
Wallpaperer
Hand trucker

Locker room attendant
Doorman
Stevedore
Watchman
Apple picker
Upholsterer
Bus boy
Bus girl
Kitchen helper
Unskilled laborer
Candy wrapper
Tile setter
Wrapper
Tree pruner
Messenger, outdoor
Office boy
Office girl
Porter
Packer
Truck helper
Laundry worker
Gas station attendant
Ironer
Saw machine operator
Bootblack
Usher
Animal caretaker
Laborer, crops
Collator
Railroad track worker
Mangle machine operator
Maid, hotel
Car washer
Shoe repairer
Window washer
Floor polisher
Newspaper deliverer
Dairy hand
Photocopy machine operator
Housekeeper
Ward attendant
Office cleaner
Mechanic's helper
Brass polisher
Waitress
Food handler
Groundsman
Textile machine worker
Fish cleaner
Bookbinding worker
Bottle filler
Parking lot attendant
Messenger, indoor
Office clerk
Janitor
Sorter
Garbage collector
Carpenter's helper
Mail carrier
Drillpress operator
Ticket taker
Manicurist
Warehouseman
Building maintenance worker
Cannery worker
Mail bag handler
Houseman
Routeman's helper
Gatekeeper
Office machine operator
Bag filler
Bellhop

Skills Training

Vocational education and special education do not overlap as much as they could. While actual job-directed training and education usually do not begin until secondary school, children have the capacity to learn about careers and jobs in their preschool and primary years. Developmentally disabled children need extra opportunities to try out and learn different kinds of prevocational skills. Older children could serve as role models for younger children by teaching them skills such as sanding, weaving, collating, and sorting in prevocational classes. The younger children could also serve as their assistants on school-generated jobs, for example taking attendance, xeroxing, custodial work, and food preparation. The older children would benefit from experiencing responsibility for a less capable worker. Also, one of the best ways to learn something is to teach it to someone else. This type of activity could be included in the individualized educational programs of both older and younger children.

Vocational centers within public school systems maintain special requirements for admission which may be exclusionary. Developmentally disabled students in need of skill-training may be kept out by unrealistic demands for eligibility. Parents need to be included in the decision-making process to re-evaluate and change these policies to best meet the needs of developmentally disabled children. Regular students would benefit too if, for example, a "buddy" system was established wherein they took partial responsibility for the training. In terms of subsequent employment in the community, it is important that students being trained for union and trades positions develop a sensitivity to the abilities and needs of the developmentally disabled. This process should begin in school. In the Summer 1978 issue of Common Sense from Closer Look, a newsletter of the Project of the Parents' Campaign for Handicapped Children and Youth (Box 1492, Washington, D.C. 20013), the following comments were made about the admissions policies of vocational schools:

> Often students are "counseled out" by guidance counselors who discourage them from applying because they don't believe they can make the grade. Parents need to know how much these old attitudes conspire to exclude handicapped students. A seventh grade reading level, for example, is required by many vocational schools, although there are many skill-levels for which students can and should be trained which require far lower reading ability.
>
> For example, jobs like dietary aides, nurse's aides, orderlies, and others in the health occupation cluster, do not require a high ability in reading or math. Yet, far too often training in health occupations is only offered to those students who can rise to the very top of the field...while we deprive thousands of people of the chance to be trained to do jobs that are very much needed by the labor market.
>
> We need to look at other problems with traditional testing. Many handicapped students must have oral tests, or tests that are not timed, or other specific accommodations in order to get a fair picture of their abilities. New methods of assessment can give a fairer and more comprehensive picture of a person's potential. Knowledge about vocational assessment is growing, and parents and teachers should look into it. There are ways of evaluating a student's performance with "work samples" (mock-ups or facsimiles of actual jobs performed in the world of work). Sensitive observations of behavior, attitudes, problems, likes and dislikes during sampling and instruction periods are part of assessment. These are combined with other kinds of information--from special teachers, psychologists, educational diagnosticians, parents and students—so that a person can be encouraged to reach his potential in a field he or she enjoys.
>
> Remember that it's almost impossible to tell if an individual can learn to perform a task unless given a chance to try it out. The traditional closed door policy of vocational high school programs has made it impossible to discover what a handicapped individual's potential may be.
>
> A few school systems now have a zero-reject policy for vocational education programs--integrating handicapped students into

regular classes to the greatest extent possible. Students--handicapped and non-handicapped--are permitted to learn at their own pace, and to reach the highest level of job competency they can attain. They are helped to seek employment at different stages; not everyone is able to reach the top level of proficiency. Classroom openings occur regularly throughout the school year, and waiting lists are kept to a minimum. This kind of admissions policy can be the rule, not the exception--if we work hard enough.

Pre-vocational and vocational training within the schools should include varying levels of work participation. At the entry level students work at jobs within the school such as xeroxing, custodial work, and care of younger children. At the secondary level, during the school year in which students attain their 16th birthday, the Illinois Department of Rehabilitation Services (DRS), formerly the Department of Vocational Rehabilitation (DVR), can contribute to career preparation. The Secondary Work Experience Program (SWEP) offered by DRS is a supplement to special education programming which provides: counseling, guidance, diagnostic evaluation, vocational evaluation, and assessment through placement in realistic employment situations. Students prepared for work in the community are paid in part by DRS, with the employer providing a fraction of the student's wage. On-the-job training is provided by the employer and supervised by a vocational teacher/counselor from the student's school. When the student attains higher proficiency on the job, the employer may hire the student for more work hours and pay the full salary. The employer, however, is under no obligation to do so.

When the student graduates and begins full-time employment, the school's responsibility for job supervision ends. If your child lives at home at this time, you must contact DRS or other agencies, such as Family Support Units' Follow Along Programs, which may be able to help guide and supervise your child's post-graduate work experience. If your child is in a supervised work situation (sheltered workshop or work activities program) or employed in the community and living in a supervised residence, there may be professional staff available to offer guidance.

The National Association for Retarded Citizens (NARC), the U.S. Department of Labor, and the state through the Comprehensive Employment and Training Act (CETA) jointly sponsor an on-the-job training project. The employer agrees to provide 320 hours of intensive training. To reimburse the training costs, NARC reimburses the employer 50 percent of the individual's entry wage for the first 160 hours and 25 percent for the remainder. The U.S. Department of Labor covers administrative costs and a portion of direct financing. The state uses CETA funds to provide additional training subsidies and in some cases to hire placement staff. The funds can be used by: work-study coordinators in the public schools, vocational rehabilitation counselors, workshop job placement specialists, and any other agencies involved in the job placement of mentally retarded persons. Materials about the project can be obtained from the national headquarters office (NARC On-The-Job Training Project, 2700 Laura Lane, Middleton, Wisconsin 53562, Telephone 608-831-1151). The

Illinois Association for Retarded Citizens On-The-Job Training Project has a much more comprehensive program for suburban Cook County (reimbursing employers 50 percent for the entire first year, covering transportation and child care for the first month, and paying for uniforms, equipment, and tools). Although they would refer residents of Lake County to the national office for specific help, they are available for consultation (telephone 312-263-7135).

Successful training for developmentally disabled persons has been developed by Dr. Marc Gold in his system called "Try Another Way." The approach of breaking tasks down into components (task analysis) was first used successfully to teach bicycle brake assembly to severely and profoundly retarded persons. The system is applicable with persons who have all ranges of disability. In addition to vocational training, the system can be used for the acquisition of daily-living skills. Training films and other materials are available (Marc Gold and Associates, Incorporated, 708 West Oregon, Urbana, Illinois 61801).

Finding and Holding a Job

Experiential learning through work experience programs during the formal school years can help to establish crossovers between the world of school and the world of work. Employers sometimes shy away from young persons in general, because of skepticism about their stability, conscientiousness, and willingness to conform to the requirements of responsible functioning as subordinates. Even if young people have the required skills for doing the job, employers question whether new employees will recognize the importance of being on time, meeting deadlines and production targets, taking directions and acquiescing to authority, working harmoniously with others, and exercising initiative judiciously. Once these capacities are demonstrated on one job, future prospects markedly improve.

Many developmentally disabled persons who do find employment perform quite well on the job. Those who do fail most often have the ability to do the work but are unable to cope with the social, personal, and interpersonal problems that arise in any employment situation. Parents and teachers must work together to help developmentally disabled children develop a concept of the dignity of work, regardless of its nature, as well as to have a sense of dignity of themselves. The kinds of work habits to be instilled, because they may be determining factors in holding onto a job, are:

1. dependability - going to school/work every day except in the case of illness or severe weather,

2. promptness - being on time for the bus, school, classes, work, and extracurricular activities,

3. following instructions - carrying out job tasks, completing assignments,

4. personal appearance - cleanliness, appropriate dress, grooming,

5. ability to work independently - being given responsibility for specific chores and tasks, and being held accountable for their completion,

6. courtesy - respect for the rights and property of others, being well-mannered,

7. acceptance of criticism - development of social and emotional maturity,

8. cooperation with fellow workers - on-the-job and in social settings such as the lunchroom and after hours.

Realism must be the key to education and training. Unlike special education, day training programs, work activities and workshop programs, entering competitive employment means developmentally disabled adults will enter a real world not truly made for them. To maximize your child's development, you must help him or her to align concepts of work with realistic job possibilities, to learn to handle social and interpersonal situations which may not always be pleasant, and to handle everyday personal problems (money, transportation, living quarters) which may not be as routine to your child as they are to you.

The Employer

Employers need to be educated too. Community acceptance is a prerequisite to meaningful employment opportunities. While individual contacts can be effective, this is really an area where group action is needed. In fact, it is probably best if your child is not hired by your own employer or by a friend because then issues of job performance can become clouded by emotional overtones. It is difficult to be an advocate for your own child unless it is part of a group advocacy effort.

To expand job opportunities, a continuing public relations/education program is needed to alert employers to the benefits of hiring the developmentally disabled. Under the Rehabilitation Act of 1973 federal agencies and companies that accept federal government contracts are required to take "affirmative action" in employing and advancing qualified handicapped workers. Non-compliance can result in court action, withholding of payments due, cancellation or suspension of a contract, and disbarment of the company or agency. About half of all American businesses have federal contracts. You can help businesses fulfill their federal requirements while developing job opportunities by showing how the special education graduate has acquired work skills which meet specific job requirements.

Many employers, federal, state and local agencies are already involved in employment opportunity expansion. The Federal Government has a special hiring program for developmentally disabled persons, who are certified by vocational rehabilitation counselors as ready to work. The person can be hired directly by a Federal agency without having to take a Civil Service exam and without being placed on a Civil Service register. It is the policy of the American Federation of Labor and Congress of Industrial Organizations (AFL-CIO) to increase employment opportunities for the developmentally disabled through collective bargaining agreements and union-management cooperation.

The local, state and federal employment offices may be good resources. Most keep track of types of jobs in the community and may be in a good position to steer a developmentally disabled person in the right direction. Local and state associations for the developmentally disabled, the governor's advisory council on developmental disabilities, chambers of commerce, service organizations (such as the Rotary Club), and the clergy are potential sources of help in finding and creating job opportunities.

An alternative to finding a job in the competitive marketplace is to create new opportunities by starting a business. The Lambs Institute periodically conducts a four-day symposium for parents, community leaders, and professionals who are interested in adapting The Lambs' approach and methods to their own communities' programs. The workshop presentations include the business work/training program (day program), the residential program, the fundraising program, and The Lambs' business concepts and principles. Workshop participants have the opportunity to observe and analyze first-hand the operation of the business/training centers. Information is provided about how the centers are organized, the levels of proficiency required for different tasks, teaching aides, equipment needed to duplicate the business, suppliers of raw products, annual sales and seasonal sales trends. Similar businesses (bakery, pet shop, restaurant, stationery shop, specialty food store) could be established individually in community shopping malls and business districts.

Another type of business is the affirmative industry operated either on a non-profit or profit-making basis. As originally developed by Minnesota Diversified Industries (666 Pelham Boulevard, Saint Paul, Minnesota 55114) and implemented by Opportunity, Incorporated in Highland Park, the affirmative industry has five major types of employees: supervisors, technicians, model workers, workers, and employees who are handicapped. The roles of the supervisor and technician are identical to those in business and industry. Model workers are experienced, knowledgeable and conscientious workers similar to shop stewards. The affirmative industry protects or shelters some positions for employees who are handicapped. An affirmative industry provides productive, gainful employment by utilizing normal business practices. (See Chapter on Parents as Planners of Programs for further ideas.)

As you plan for your child's vocational needs, you may want to contact and meet with local private agencies. Even if your child is in a public school program, the staff at private agencies (for example, Countryside) might know about different vocational options than does the regular school counselor.

Vocational Interest Areas

AUTOMOTIVE INTEREST means preference for occupations concerned with parking, cleaning, polishing, lubricating, and refueling trucks, buses and automobiles and related servicing and maintenance activities of vehicles.

BUILDING TRADES AND LIGHT INDUSTRIAL INTEREST means preference for mechanical activities concerned with assembly, repair, construction, and installation work using hand tools, machinery, and light or heavy equipment.

CLERICAL INTEREST is an interest in general office work concerned with running errands, sorting and delivering letters, packages, and messages; furnishing workers with clerical supplies, and performing routine tasks in an office, library or printing firm.

ANIMAL CARE INTEREST indicates a preference for activities concerned with feeding, watering, sheltering, exercising, and grooming animals, and cleaning quarters and equipment.

FOOD SERVICE INTEREST means preference for occupations involving the preparation and serving of food, and clean-up tasks in kitchens and dining areas in restaurants, hotels, motels, and clubs.

PATIENT CARE INTEREST is a preference for occupations concerned with attending to the physical comfort, safety, and appearance of patients, and performing routine tasks in hospitals, clinics, morgues, or related health facilities.

HORTICULTURE INTEREST indicates a preference for activities concerned with planting, tilling, cultivating, gathering and harvesting plant life or plant-life products, and caring for such areas as gardens, grounds, parks and cemeteries.

JANITORIAL AND HOUSEKEEPING INTEREST means preference for occupations concerned with cleaning and upkeep of building interiors, furniture, and equipment in hotels, motels, stores, and other facilities, and cleaning tasks in and around private households.

PERSONAL SERVICE INTEREST indicates a preference for activities that involve helping, assisting, and serving people in a broad range of services such as barber, beauty operator, ticket taker, usher, child day care aide, and porter.

LAUNDRY SERVICE INTEREST is a preference for occupations that involve laundering, dry cleaning, pressing, ironing, dyeing, and repairing of clothing, furnishings, and accessories in commercial laundries, dry cleaners, launderettes, or private households.

MATERIALS HANDLING INTEREST is an interest in occupations concerned with warehousing, loading or unloading, storing, stacking, and hauling or delivering of merchandise.

Recommended for Further Reading

Bolles, Richard Nelson. What Color Is Your Parachute? Berkeley, California:
1977 Ten Speed Press.

Readable manual with practical step-by-step instructions for identifying job interests, evaluating job possibilities, and conducting a job-hunt. Can be used by parents and professionals working with developmentally disabled persons.

For more information on vocational education and employment opportunities for the handicapped contact:

The President's Committee on Employment of the Handicapped
1111 20th Street, N.W.
Sixth Floor
Washington, D.C. 20210

The President's Committee on Mental Retardation
330 Independence Avenue, S.W.
South Building, Room 3232
Washington, D.C. 20201

AFL-CIO
815 Sixteenth Street, N.W.
Washington, D.C. 20006

Living Environments

There are many types of living environments suited for different ages and developmental levels. Depending on your child's developmental abilities and the family's situation financially and emotionally, you may not be able to (for younger or older children) or want to (for young adults) have your child remain at home. It is usually very difficult for any parent to have their child leave home, regardless of the child's age. But it is an eventuality which will almost certainly occur. Such a decision is not to be taken lightly and should be preceded by input from professionals.

Occasionally, it is necessary to place a child at birth or shortly thereafter. This happens very rarely now with the availability of early intervention programs. However, if a child requires 24-hour medical attention and is profoundly handicapped, placement may be the only workable solution for the family. Whether a child is placed directly from the hospital or shortly thereafter, parents should feel content that they are providing the best parenting possible by maintaining regular contact. A regular visitation schedule should not be made too demanding so as to make a hardship on other family members or establish unattainable expectations. For example, planning to visit every weekend would undoubtedly be interrupted by illness, severe weather, or other demands. Once a month might be a more reasonable goal. Special cultural holidays (especially Christmas) are important, but very busy times for families; the weekend just before or just after might provide a more relaxed and rewarding visit for both the child and the family. For their own peace of mind parents should become acquainted with the professionals who care for their child. For the sake of their child's best interests, parents should be supportive of professionals to foster a climate of trust, calm and balance. Professionals will be caring for the physical needs of the child; parents fulfill important emotional needs.

Decisions surrounding your child leaving home as an adult will be just as difficult but involve different considerations. These will be discussed at the end of the chapter. Alternative living environments available and suggestions for evaluating these environments will be discussed first.

Alternative Living Environments

The types of public and private programs that are supported by state funding through the Illinois Department of Mental Health and Developmental Disabilities are as follows:

A skilled nursing home is a facility which provides skilled nursing and related care. These facilities have 24-hour nursing services directed by a qualified RN, a charge nurse (RN or graduate LPN), for each shift and as much additional staff as required to meet the licensure standards. These facilities normally serve a population from birth to age 20. In addition to 24-hour nursing care, additional activity and physical therapy programs are normally provided as part of meeting the client's habilitation needs.

An intermediate care facility is a licensed nursing home which provides medical supervision. The facility must have 24-hour nursing services with a director of nursing, additional licensed nursing staff according to the number of occupied beds, and as much additional staff as required to meet the licensure standards. Most of the patients have long-term illnesses or developmental disabilities which have reached a relatively stable plateau and require only simple nursing care. In addition to nursing services, rehabilitative nursing, activity programs and social rehabilitation programs are normally provided. These facilities normally serve a population from birth to age 20.

Sheltered care homes provide services to residents who are not in need of professional nursing care, but are in need of personal assistance and supervision. Sheltered care homes may have, but are not required to have, nursing personnel. Activity programs and social rehabilitation programs are the main service. Vocational training services are to be provided through community agencies. These facilities normally serve a population from birth to age 20.

Residential schools are designed to meet the needs of developmentally disabled children who can no longer continue to reside in a family setting and can no longer participate in a public school program. They provide room and board, educational programs (certified by the Illinois Office of Education), behavior management services and habilitation programs. Residential schools are encouraged to utilize community resources whenever possible. Through the use of social services staff the family is encouraged to remain involved in the child's program. Residential schools are also responsible for the provision of psychological services, speech services and audiology services, dental services, physical and occupational services and nursing services. They are encouraged to provide the necessary programs in a "normalized environment." The goal of residential schools is to develop the child's potential for return to a family setting and the public school system.

Foster homes are designed to meet the needs of developmentally disabled children who can benefit from the care and interaction of family living, but who have no natural family willing or able to meet their needs. With the room and board provided by the foster family, the child participates in either a day treatment program or the local school system during the day-time. The goal of the foster home program is that the family system will allow a developmentally disabled child to reach his or her maximum potential in an environment as normalized as possible. The foster family develops the child's community awareness by including the child in the family excursions, i.e., shopping, eating in restaurants, trips to the zoo, etc. The foster family's composition must be appropriate for meeting the child's needs. The foster family must possess an ability to understand behavior, the desire to help and a willingness to cooperate with Department of Mental Health and Developmental Disabilities staff in providing a program that will meet the child's needs.

The foster training program is similar to the traditional foster home program in that it is designed to meet the needs of developmentally disabled children who can benefit from interaction of family living. Foster training homes, however, also provide training for the foster child in the areas of self-help skills, social, behavior management and other needs as identified by the regional/supervising agency staff in conjunction with the foster training home parents. The foster training home parents are responsible for providing documentation of structured habilitation programs. Community resources are utilized wherever possible. The goal of the foster training home program is to allow children who are more substantially handicapped than traditional foster children to reside in a family setting.

Child group homes are designed to meet the needs of developmentally disabled children who can benefit from the structure and programs provided in small group living. Child group homes provide services for 10 children or less with the children participating in community oriented programs. The community programs range from private day care to local public schools. Since the daily programming is obtained in the community, the group home staff remain responsible for providing recreational services and habilitation programs in the evening hours and during the time that the client would normally participate in self-help skills areas. The goal of the child group home is to prepare the child to return to a family setting.

The home intervention and training program is designed to allow a child to continue residing with the child's natural family yet receive intervention and training from a licensed child welfare agency. The child welfare agency provides staff to go into the natural family's home for the purpose of: (1) initially assuming total management of the developmentally disabled child during the in-home assignment period; (2) participating in inservice training programs with natural family members; (3) developing a habilitation plan in conjunction with the natural family for phasing out agency services as the family becomes more comfortable with working with their developmentally disabled child. The children in this program normally participate in community day programs. The home intervention trainer is with the natural family in the evenings and also for weekend relief. This program provides respite services for the family allowing them to spend time with other children or to be outside of the natural home. It also allows the natural family to have a resource person working with them directly to sharpen their skills in working with the child. The goal of this program is for the natural family to become the primary individual providing program services to their child while the child is in the natural home.

Respite care service is designed to prevent long-term residential placement and/or institutionalization by utilizing early intervention. Respite care allows parents to place their child into a short-term program. This allows the family to take a vacation, spend additional time with other children in the home, take time out for hospitalization or medical service, or have time in which they can rest. Settings for respite care allow for children or adults to receive separate respite services at any given time.

Some respite settings are able to receive the client for behavioral management purposes and/or medication evaluation and crisis intervention. The goals for respite programs are two-fold: 1) To allow a family a short amount of time away from the client for their own personal reasons; 2) To provide a setting where clients can receive short-term intervention when they are exhibiting a behavioral/medical problem or are involved in a family crisis. In either case, return to the natural home, foster home, or other placement resource normally occurs within four to six weeks or less. Respite care can occur in a variety of settings (i.e., natural family home, foster homes, group homes, private child care institutions, ICF/DD, skilled nursing, etc.).

An Intermediate Care Facility for the Developmentally Disabled (ICF/DD) is designed to meet the social and rehabilitation needs of developmentally disabled adults. Major emphasis is upon obtaining appropriate services in community-based settings. The ICF/DD does provide simple nursing care, but the focus of the program is upon activity and habilitation programs. The facility must have 24-hour nursing service with a director of nursing and as much additional licensed nursing staff according to the licensure standards. Supportive staff are available as required to meet the needs of the residents.

Through its direct program and consultative services staff, the community living facility provides for: the transitional return to the community from institutions, the possible prevention or delay of placement in an institution, a home for residents, if they meet program criteria, and training for totally independent living. The function of community living facilities is to normalize living conditions and, as far as possible, to replicate home-style living as it exists in the community. Consultative services staff may include social workers, psychologists, speech and hearing specialists, audiologists, psychiatrists, registered nurses and other consultants, as necessary. Community living facility residents must be eighteen years old or older.

The supported living arrangement (SLA) provides support and direction so as not to interfere with the individual's independence, but rather to support and shape the adult with the necessary skills for total independence and self-sufficiency. Support shall be provided by staff on an "as needed" basis, based on the individual's capabilities. Through its direct and consultative services staff, the supported living arrangement provides for: support and direction leading to totally independent living; residence for clients who have attained self-help and semi-independent living skills; the transitional return to the community from facilities that are relatively more restrictive; a variety of types of living arrangements that enable handicapped persons to enjoy choice and options comparable to those available to the general population; and a comprehensive approach that makes provisions for the total environment, including a service plan designed to sustain a normal, community-based living arrangement. The function of the supported living arrangement is to normalize living conditions and, as far as possible, to replicate home-style living as it exists in the community. Supported living arrangement residents must be 18 years of age or older, demonstrate ability to self-administer medication if needed, demonstrate competence of basic self-help and survival skills, and have vocational employment in either workshop or community.

The adult family home program is a unique modification of the foster care program for children. The program consists of placing one to two developmentally disabled adults in a carefully selected private home in which a resident can live as a family member and receive care and/or training. The adult family home seeks to combine all of the qualities and features unique to family living. Adult family home placements are dynamic. They are not necessarily meant to be a life time residence. The goal of this program is to maximize the individual's potential and then, if appropriate, move him/her to a setting which will provide even greater growth. If an individual no longer needs the supervision and interaction which the family can provide, then he or she should be moved to a more independent environment.

Other programs are in the planning stages such as assistance for individuals in maintaining independent living status. Keep in touch with the Department of Mental Health and Developmental Disabilities for changes in existing programs and the creation of new alternatives. The Department is the major source of funding for any residential program for the developmentally disabled in Illinois.

Evaluating Living Environments

In deciding upon an alternative living environment for or with your child there are a number of factors which you will want to evaluate before making a decision. Some suggestions to help you as you explore different options are the following:

Residents--number, types of disabilities represented, average age of residents, what happens if the placement does not work out?

Staff--number, types of professional services represented, availability?

Physical Appearance--sound structurally, clean and attractive, adequate heating and air conditioning, enough room for residents to live comfortably, rooms individualized with personal belongings and posters, does the neighborhood seem safe?

Programs--educational, social, recreational, vocational, medical, dental, volunteer, community involvement, handling of hygiene, laundry, housekeeping and emergencies?

Interpersonal--attitude of residents and staff towards each other, response of residents to visitors, activities in which residents are involved, restraints on residents, adequate privacy and space for leisure activities?

Make sure you visit more than once or over a long enough period of time to be objective about your feelings about the living environment. Try to imagine your child in that setting. Will he or she fit in? Try to ask yourself whether you want someone you care about living there. If it is not appropriate investigate to see if there are any better alternatives. It may be that there is something you can do to bring about improvements, either as an individual volunteer or by working with a parents' organization or state agency.

The Meaning of Establishing Independence

If your child has remained at home while completing his or her period of formal education, or will be returning home because an educational program terminates at age 21, you will want to examine the possibility of having your child remain at home as a young adult very carefully. It is a choice assuming that both parents and young adult are agreeable to the idea and the situation. The obvious advantage is that you will continue to provide a non-threatening, accepting environment with people who are genuinely sympathetic. Issues to be considered are as follows: What will happen when you are unable (due to age, financial ability, or illness) to care for your child? How will the young person socialize with peers and others in the community? Will there be difficulty allowing your child to "grow up" with adult responsibilities, while still under your protection and supervision?

As parents of a developmentally disabled child, you should be concerned about your child's future after leaving school. Until that time your child will be well supervised academically and socially, and be involved in vocational training. Counseling, social workers, vocational rehabilitation workers, physical therapists, and other school personnel will be accessible. Most of these services are provided by your local school district or special education school. As your child finishes formal schooling, matures and grows into an adult with all the needs and requirements of an adult, that support system may not be as readily available. You will have to ask yourself what you can best do as a parent to ensure that the developmental process continues.

The developmentally disabled adult continues to grow and change. As any person develops, needs also change. You may want to support the transition to an alternative living environment while you are still available to do so, rather than have it abruptly forced upon your child if something happened to you. It is usual in our society for young adults to establish their independence by living apart from their parents; it is also usual for parents to continue to be supportive of their children well into adulthood, emotionally and often financially as well. Helping your child become independent of you does not mean abandonment, but rather that a new relationship between caring adults can be established.

Community Acceptance

As opposed to looking for a job, there is no similar urgency to begin exploring alternative living environments. You will have to make the decision as to whether your child can handle the transition to work and community living simultaneously or whether it may be easier for your child to remain at home for awhile after beginning to work.

There are very few community living alternatives available at this time. Waiting lists for existing residences are usually quite long. It may be necessary for you to start exploring living alternatives several years before you and your child will be making this transition; a good time to begin would be while your child is in high school. The trend is toward small, community-based living alternatives. Two barriers exist to prohibit the expansion of these alternatives: one is financial, the second is attitudinal. Overcoming both involves long-term group effort. The group need not be large, but should enlist persons with organizational expertise. For example, even after the Glenkirk Association acquired the property for a residential home it took seven years to meet all the guidelines and obtain the necessary clearances.

A case study example of the determination and persistence needed to follow through on plans for a community living alternative is the Moraine Association. The idea began with two parents in 1974. One had been a board member of the Illinois Association for Retarded Citizens and had a knowledge of options available for developmentally disabled adults. Their first step was to secure a start-up grant from the Illinois Department of Mental Health and Developmental Disabilities and a contract for funding programs when the facility was opened. They looked for a site, found a building, and raised money for the down payment, but the owner sold to someone else after several months of negotiation. They received financial support through the City of Highland Park, found a site, and purchased it.

This is the route any group would have to follow--obtaining state endorsement first, and local support second. During this time-consuming process you will realize what a big bureaucratic machine the governments are in terms of paperwork and accountability requirements. As a parent you will be frustrated, but as a taxpayer you will be pleased to find out how carefully tax monies are spent. For example, you will probably need to provide projections about staffing requirements and programming, document that your new service does not duplicate another, and demonstrate economic feasibility. Public hearings may be involved before you receive a permit which would also serve as a prelicensing. During this time, members of your organization will have to monitor legislation, and attend meetings. Your organization will need to enlist the services of lawyers and financial consultants to negotiate loans and fill out forms. It takes time but others have done it and are available as consultants through the community living facilities' directors group which is organized at the regional level.

Whether your child will live independently, or will live at a new facility, community acceptance is the key to successful and amicable living arrangements. The groundwork should be laid in advance. Proposed facilities have failed to become reality because the community has opposed them through zoning restrictions. Public relations is an ongoing effort. As you and the schools encourage your child to participate in more and more community activites, this will help in arriving at the day when developmentally disabled adults are accepted as neighbors, with capabilities and limitations very much like everyone else.

Recommended for Further Reading

The associations for the developmentally disabled publish lists and materials on residential alternatives. For example:

United Cerebral Palsy Associations, Inc. Professional Services Program Department 66 East 34th Street New York, N.Y. 10016	ask for: No Place Like Home by Irving R. Dickman.
Governmental Affairs Office National Association for Retarded Citizens 1522 K Street N.W., Suite 516 Washington, D.C. 20005	ask for: Government Report, news bulletins which explain legislation and cite trends
Research and Demonstration Institute National Association for Retarded Citizens 2709 Avenue E East Arlington, Texas 76011	ask for: The Parent/Professional Partnership: How to Make It Work
Director of Residential Services Illinois Association for Retarded Citizens Ridgely Building, 504 East Monroe Springfield, Illinois 62701	ask for: Residential Visit and Evaluation Guide and lists of residential alternatives
Information and Referral Service National Society for Autistic Children 306 - 31st Street Huntington, West Virginia 25702	ask for: Directories of facilities and other lists (over 40 are available by state, county, and subject matter)

Specialized Programs, Division of Developmental Disabilities, of the Illinois Department of Mental Health and Developmental Disabilities at 401 S. Spring Street, Springfield, Illinois 62706, would also be able to provide lists of all residential alternatives funded by the Department which would cover most alternatives in the state as well as program and service guidelines.

FAMILY SUPPORT

Families with developmentally disabled children experience needs beyond those which are met through special education. Health care, family counseling, recreation, community services, financial planning, and considerations about having more children are areas where support is available.

Developmentally disabled children need the same regular medical, dental, and other health care services that every child needs while growing up. Parents may find it difficult to get these services because not all doctors, dentists, audiologists, and other medical professionals work with handicapped children. The Chapter on Health Care Services describes how to locate professionals and services, as well as how to complement professional care with practices in the home that promote physical well-being. Topics covered include: medical services, dental services, vision screening, communication disorders, hearing problems, special equipment repair, and nutrition.

When a baby is expected, the family is usually excited. But no matter how much parents want the baby, or how much they have read, there are some things they are not prepared for. The arrival of a baby changes the family's lifestyle. Besides dealing with unexpected things that all parents encounter, the parents of a developmentally disabled child have to cope with special considerations, too. It is sometimes hard for parents to carry out everyday activities like going to work and taking care of the house. The Chapter on Family Counseling discusses some common emotional responses and provides information about types of counseling services.

Few groups have more leisure time than the developmentally disabled. Too often their free time has been forced upon them because of their disabilities and lack of planned opportunities for recreation. Learning how to plan and use leisure time effectively can mean the difference between a boring, sedentary life and an active life of increased fitness and sharpened artistic, recreational and social skills. The home is the ideal place for learning to use leisure time effectively. Family recreational activities that the child enjoys and does well in can become life-long hobbies or turn into vocations when the child reaches adulthood. For example, a hobby such as gardening can turn into a job in a nursery. A number of recreation programs, both public and private, are also provided in Lake County. The Chapter on Recreation discusses family and community activities.

The Chapter on Community Services discusses types of support available to families with developmentally disabled children. Information and referral services can expedite the search for help. Baby-sitters, respite care, and homemaker/home-health aides can make caring for the household and family less of a burden, especially if a family member becomes ill. Mobility for the developmentally disabled child can be enhanced through police cooperation and experience in using public transportation.

The Chapter on Financial Planning discusses the coordination of government and private services to reduce the economic burden which may be associated with a disability. Health insurance and governmental benefits are highlighted. The merits of guardianships, trusts and wills are discussed as ways of providing on-going protection for the developmentally disabled child into adulthood.

Parents and siblings of a developmentally disabled child may wonder what the chances are that another child born into the family could be developmentally disabled. The Chapter on Considerations About Having More Children addresses such concerns. Some of the questions can be answered through genetic counseling. During pregnancy medical procedures such as amniocentesis can determine if some genetic or biochemical disorders are present. Proper nutrition during pregnancy can prevent disabilities associated with low birthweight. Risks incurred from cigarettte smoking, alcohol consumption, and prescription and over-the-counter drugs can be monitored or eliminated. Perinatal centers have special staffs and equipment to handle problems arising during labor and delivery. And, while children are growing up, routine preventative measures for illnesses and accidents can prevent serious disabilities. Accidents and poisonings cause more fatalities and crippling injuries than birth defects and disease.

Health Care Services

Your child will need the same regular medical, dental, and other health care services that every child needs while growing up. You may find it difficult to get these services because some doctors, dentists, audiologists, and other medical professionals are reluctant to work with handicapped children. You may find yourself contacting everyone you can think of to get someone to fix your child's broken wheelchair, walker or other special devices.

Special help is available to you and your child to help overcome the obstacles you face daily in trying to keep your child healthy. Many organizations and persons can help you. This section advises you where to find the medical, dental, and other health professionals that your child needs. It also suggests what you can do at home to supplement the treatment and training your child receives from health care professionals.

Medical Services

If you are new to Lake County and need or want to switch family doctors, you may have a hard time locating a family doctor or pediatrician to handle your child's illnesses and regular check-ups. Doctors do not advertise their services except in the yellow pages of your local telephone directory and through the Physician Referral Service of the Lake County Medical Society, located at 226 Genesee Street, Waukegan, phone: 662-7766. The yellow pages group doctors alphabetically and by specialty. The referral service only names doctors in your area that are in good standing with the Lake County Medical Society. One good way to find out which doctors work with handicapped children is to ask the nurse at your child's school, or to ask other parents in your child's school. If your child is not enrolled in school, contact the special education office of your local school district and ask for the telephone numbers of the nurse and the president of the parents' organization. The school nurse will give you the names of doctors who work with children from the school. To get opinions on which doctors are the best, talk to the president of the parents' organization and to the parents of other developmentally disabled children. Talk to them at a parents' organization meeting or get their telephone numbers and call them. Additionally, the Lake-McHenry Regional Program, the Low Incidence Cooperative Agreement (LICA) Program of the Northern Suburban Special Education District (NSSED), and the Glenkirk Association for the Retarded sponsor parent-infant education programs for 0-3 and may provide lists of doctors who work with handicapped children.

In addition to doctors in private practice, the Lake County Health Department has facilities for examination and treatment of illnesses and injuries on an out-patient basis at the Belvidere Medical Building in Waukegan and the Midlakes Medical Building in Round Lake Park. A mobile van travels to townships in the county. The van is staffed by a physician and other health professionals. For information on the clinic hours and other services of the

Lake County Health Department, consult the directory in the back of this manual.

The six Lake County hospitals have emergency rooms staffed round-the-clock by physicians. The hospitals are American International in Zion; Condell Memorial, Saint Therese, and Victory Memorial in Waukegan; Highland Park Hospital; and Lake Forest Hospital. A seventh, Good Shepherd is scheduled to open in October, 1979, in Barrington.

To protect your child in emergencies requiring medical help, there is a means to alert emergency workers to your child's medical problems, allergies, or regular medication. Emergency medical information cards, bracelets, and neck tags list your child's medical problems (for example, epilepsy, autism, diabetes, cerebral palsy, recurring unconsciousness, or limited sight and hearing), the medicines taken regularly (for example, anticonvulsant drugs) and/or dangerous allergies (such as reactions to penicillin, feathers, or common foods). Your child should wear and carry this information at all times. Medi-Check International Foundation, Inc., at 2640 Golf Road, Glenview, Illinois 60025, sells these medical information cards, bracelets and neck tags.

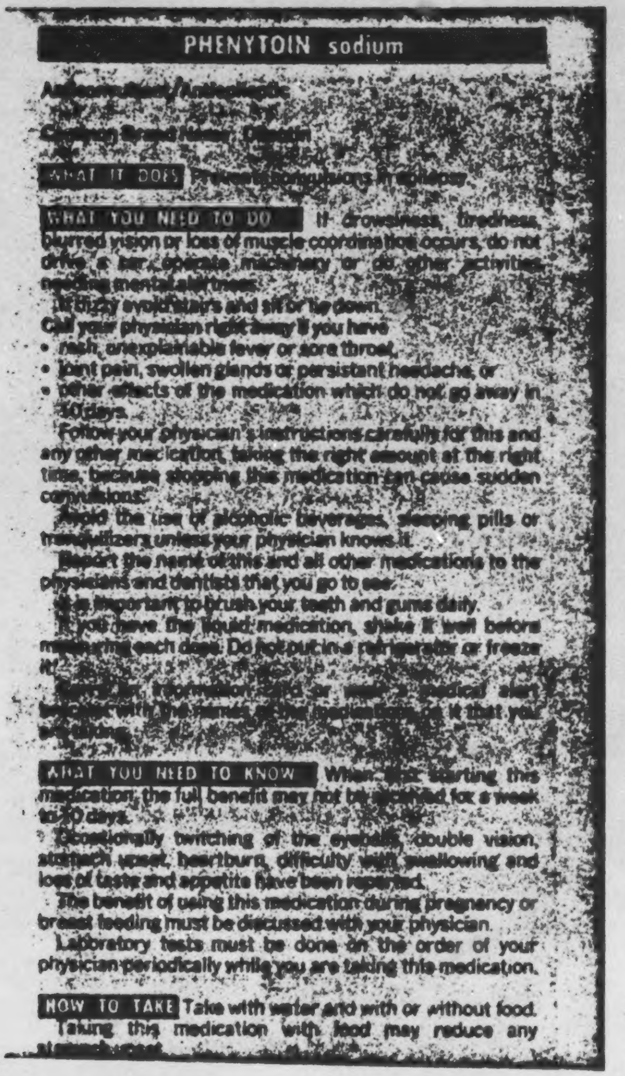
Some children take medicine regularly to help relieve their medical problems. For example, persons with epilepsy often take anti-convulsant drugs to help them remain free from seizures. These drugs may cost hundreds of dollars each year. Buying in large quantities (within the limits imposed by federal and state laws) is one way to save money.

The Epilepsy Foundation of America runs a pharmacy service in its Chicago offices that buys drugs in large quantities and passes on the cost savings to their members. To take advantage of this service you must be a member.

Additionally, other non-profit and commercial organizations sell medications at reduced prices. Also, prices vary from place to place, so you might compare various retail outlets in the community.

Most medications have some side effects. If these side effects are not known, it may worry parents and their families. Patient Prescription Information, Inc., sells information sheets that pharmacists include with each prescription they fill. One side of the information sheet describes the drug, tells what it does, tells what you need to know about its side effects, and explains under what conditions the drug should be taken. The other side includes general information relevant to any prescription. At this time, the information sheets are available only through pharmacists participating in the program. Patient Prescription Information, Inc., is planning a book of information sheets on all drugs. If your pharmacy has not heard of this or similar service, encourage the store to take part for the benefit of all its clients. An example* of the information sheet on the anti-convulsant drug, Dilantin (generic name, Phenytoin Sodium) follows on the next page.

Unwanted side effects can be caused not only by a single drug, but by a combination of different drugs taken at the same time. If your child takes medication regularly make your dentist, doctor, and pharmacist aware of all medications that your child is taking before they prescribe more. Also, ask if there are any non-prescription drugs (such as aspirin or cold remedy drugs) that could be harmful if taken with your child's regular medication.



PHENYTOIN sodium

Anticonvulsant/Antiepileptic

Common Brand Name: Dilantin

WHAT IT DOES Prevents convulsions in epilepsy.

WHAT YOU NEED TO DO If drowsiness, tiredness, blurred vision or loss of muscle coordination occurs, do not drive a car, operate machinery or do other activities needing mental alertness.

If dizzy avoid stairs and sit or lie down.

Call your physician right away if you have

- rash, unexplainable fever or sore throat,
- joint pain, swollen glands or persistent headache, or
- other effects of the medication which do not go away in 10 days.

Follow your physician's instructions carefully for this and any other medication, taking the right amount at the right time, because stopping this medication can cause sudden convulsions.

Avoid the use of alcoholic beverages, sleeping pills or tranquilizers unless your physician knows it.

Report the name of this and all other medications to the physicians and dentists that you go to see.

It is important to brush your teeth and gums daily.

If you have the liquid medication, shake it well before measuring each dose. Do not put in a refrigerator or freeze it.

[illegible] information card or wear a medical alert [illegible] with the names of the [illegible] that you [illegible]

WHAT YOU NEED TO KNOW When first starting this medication, the full benefit may not be realized for a week to 10 days.

Occasionally twitching of the eyeballs, double vision, stomach upset, heartburn, difficulty with swallowing and loss of taste and appetite have been reported.

The benefit of using this medication during pregnancy or breast feeding must be discussed with your physician.

Laboratory tests must be done on the order of your physician periodically while you are taking this medication.

HOW TO TAKE Take with water and with or without food.

Taking this medication with food may reduce any stomach upset.

*With permission of Patient Prescription Information, Inc., Chicago, IL.

Dental Services

Dental health problems frequently occur in children with handicapping conditions. Dental problems can be caused by the disability, its treatment, normal "wear and tear", or other reasons. Missing teeth, malocclusion (crooked teeth), underdeveloped, pitted, or irregular enamel (enamel hypoplasia), periodontal (gum) disease, and grinding of teeth (bruxism) are a few examples of dental problems caused by disabilities. Drug therapy can also effect your child's mouth. Dilantin, an anti-convulsant drug used to help control seizures, may cause the gums to grow abnormally over the teeth (gingival hyperplasia) and to interfere with chewing. Prolonged use of some drugs (such as tetracycline, an antibiotic) can cause stains on both primary and permanent teeth. Immunosuppressive drugs used with blood disorders can cause sores in the mouth. Tranquilizers and barbituates can cause a reduction in the flow of saliva. This makes teeth more susceptible to decay. The dentist should know about all drugs your child is taking in order to provide the best treatment for such side effects.

Apart from these special dental problems, most handicapped children's oral problems are caused by the same diseases that damage anyone's teeth: tooth decay and periodontal (gum) disease. This happens when teeth are not cleaned and cared for every day. This damage and the resulting discomfort can be prevented almost completely with good home and professional care.

There are three general causes of dental problems: plaque, susceptibility to decay and sugar. Plaque is a sticky, colorless film of harmful bacteria that forms constantly on teeth. If not removed at least once daily with brushing and flossing (a process using thin, specially coated string to clean between teeth), plaque build-up can cause tooth decay and gum disease. Plaque removal is one of the best ways to control tooth decay and periodontal (gum) disease. Thorough brushing at least once a day with a soft bristled brush does the job best. Flossing, if at all possible, improves the cleaning process. Your dentist or school nurse can teach you the proper techniques for brushing and flossing.

Some people's teeth are more susceptible to decay than others. Fluoride can make teeth less susceptible. Fluoride can be applied in the dentist's office, used at home (in fluoride mouth rinses, tablets, and fluoride toothpastes), and consumed in drinking water fluoridated by some municipal water suppliers. Consult your dentist concerning the best approach for your child.

Sugar is another major cause of tooth decay. The more often you eat sugar and the longer it stays in your mouth, the more harm it can do. To prevent decay from starting, avoid sweet snacks (including dried fruits like raisins). But if sweets are to be served, include them with the meals so that sugar will not coat the teeth.

It may be difficult or even impossible to teach your child to brush without help from one or several persons. Several organizations publish pamphlets that suggest how to adapt toothbrushes for use by the handicapped and how parents and others can hold their children to clean teeth effectively. Write to the American Dental Association, 211 East Chicago Avenue, Chicago, Illinois 60611, for a free booklet called Caring. The National Easter Seal Society for Crippled Children and Adults, 2023 West Ogden Avenue, Chicago, Illinois, 60612, sells Toothbrushing and Flossing: A Manual of Home Dental Care for Persons Who are Handicapped for $1.50. The National Foundation of Dentistry for the Handicapped, 1726 Champa Street Suite 422, Denver, Colorado 80202, sells Home Dental Care for the Handicapped Child for $1.50. Your dentist or dental hygienist can also give you tips on how to adapt toothbrushing and flossing to your child's disability.

For professional dental work, you may have trouble finding dentists who will work with your child because of the specific disability. The nurse at the special education school probably knows the dentists who work with handicapped children. If not, the Academy of Dentistry for the Handicapped, 1726 Champa Street Suite 422, Denver, Colorado 80202, has a directory which lists members of the Academy who will accept handicapped people for clients.

In addition to private practice, several teaching hospitals with dental schools sponsor special clinics for handicapped people. At these clinics, the children receive screening, treatment and preventive services. The first visit involves a screening process to determine if the child can be managed in a dental chair or needs to have dental work done under a general anesthesia. If it is possible, dental x-rays and a mouth examination are done to detect caries (cavities) or other dental problems. The majority of cases are handled in the dental chair, which is much cheaper than having the dental work done in the operating room under a general anesthesia. At this first visit, the dentist will explain the child's dental problems to you and will tell you the best method of treatment. If general anesthesia is needed for the dental work, the dentist may schedule an overnight stay for the child, or the child may be released the same day.

An important service offered by the clinics is the prevention program. Patients make appointments to learn how to take care of their teeth. Parents are encouraged to participate and learn the proper methods and diets that are appropriate for good tooth care. Diet counseling and fluoride supplements are recommended to children whose diets lack the necessary vitamins and other foods that help keep teeth strong. Illinois Masonic Hospital conducts screening services at schools for handicapped children upon the request of the school district.

Vision

Vision screening is a service that is usually offered each year by the school your child attends. If the school does not offer it, contact the Lake County Public Health Department which offers free vision screening as part of the Nursing Services program. If it is determined that your child may have vision problems, contact vision specialists. Ask school nurses to recommend some.

The optometrist examines eyes for defects and faults of vision. The optometrist can prescribe corrective lenses and exercises, but cannot prescribe drugs for allergies or infections. Optometrists are listed in the yellow pages of the telephone book under "Optometrists".

The ophthalmologist is a physician who specializes in the study and treatment of defects and diseases of the eye. Ophthalmologists can offer more complete examinations of the eyes than optometrists, but charge more. Ophthalmologists are listed in the yellow pages of the phone book under "Physicians-Ophthalmologists".

Prescriptions for eyeglasses or contacts are filled by the optician, a maker or dealer in optical items and instruments who grinds eyeglasses to prescription. Opticians are not trained to examine eyes, but can fit your child with frames and lenses. Most optometrists offer optician services as part of their business, while ophthalmologists usually do not.

Communication Disorders

Children with developmental disabilities often are delayed in learning to speak. Their mental and motor development may be slower than their physical growth, so they may not speak at the expected ages. This is sometimes complicated by physical disabilities that make it difficult or impossible for the child to form the correct sounds.

But having speech problems does not mean that a child cannot communicate. Communication involves other senses, too. People use their eyes, ears and other parts of their bodies to give and receive information.

Parents notice that children are behind in language development when their children do not reach certain levels of development by a certain age. Here is a simple guideline: If a child has not started to talk by the second birthday, it is time to look into the problem. By the third birthday much valuable time has been lost. To judge whether a child is delayed in language development, speech and language clinicians have developed checklists with the age ranges appropriate for various levels of language development. A good book that contains such a checklist and techniques for teaching your child to communicate is Your Developmentally Retarded Child Can Communicate: A Guide for Parents and Teachers in Speech, Language and Non-Verbal Communication, by Julia Molloy and Arlene Matkin.

If your child is behind in learning to talk, do not rush to someone who claims to work wonders or guarantees speech in just a few lessons. Go to a clinic where more than one person will study your child. The Lake-McHenry Regional Program is a good place to start if your child is less than three years old. Also, the diagnostic clinics mentioned in the Diagnosis and Assessment section of Chapter I often have special clinics for communication disorders. Northwestern University in Evanston, Illinois, has a clinic that specializes in the diagnosis and treatment of communication disorders.

Two important parts of communication are speech and language. Speech is the production of sounds put together in such a way that a certain meaning is intended to be understood by another person. Language is a system for putting together meaningful sounds and movements, plus hearing and understanding sounds and movements; it is the entire give-and-take of exchanging ideas by meaningful sounds, movements and gestures.

In speech and language therapy your child will learn important communication skills. Communication is a social skill which your child can only learn through interaction with others. Your child may only spend a few hours each week with a speech and language therapist, so it helps if you reinforce the child with lots of communication at home. By working with techniques learned from the speech and language clinician you can ensure consistency in what your child is learning.

Verbal and Non-Verbal Communication

Children with communication problems can be classified as verbal and non-verbal. Verbal children can talk; non-verbal children cannot. Strategies for teaching vary, but children must first learn receptive language before they learn expressive language. Receptive language is a process progressing from learning to listen to attention-compelling stimulations (for example, calling out a child's name and the child responding with attention of some sort) through listening and reacting to sound (such as marching or clapping to music) to listening and responding to sound (for example, learning to react to the commands "Stop," "Wait," "Hot," "Look," and "Come here."). After the children have a grasp on receptive language they can learn forms of expressive language.

Non-verbal children have many different ways of communicating with others. A useful form of communication for non-verbal children (and children who make sounds which cannot be understood) is total communication. In total communication the therapists use speaking and manual signs, gestures, and finger spelling simultaneously. A handicapped child who learns total communication may acquire a means of communication at the earliest possible age. The therapists build on whatever abilities the child has to help the child communicate. The eventual goal with all children is good, usable speech.

Alternate Methods of Communication

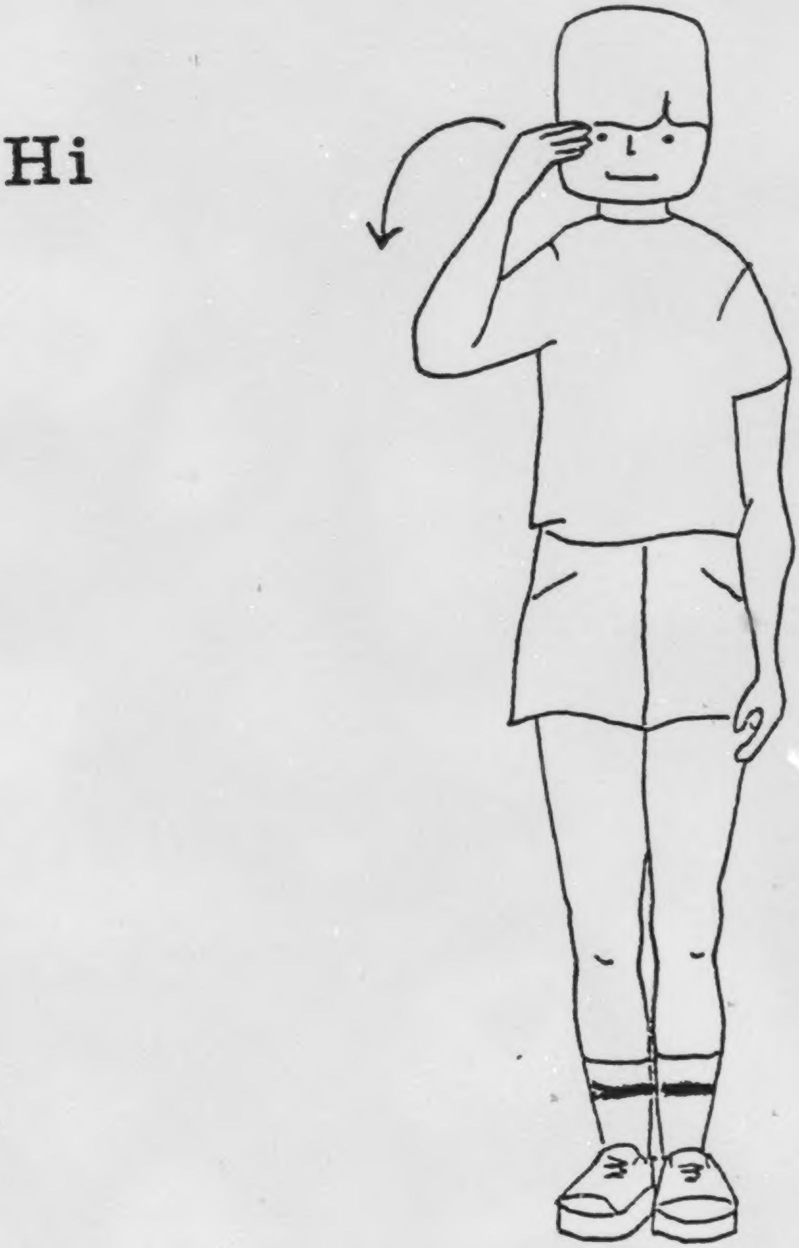
The alternative communication methods described below start with simpler ones used with children who have very little expressive language and advance to more complex ones used with children having better expressive skills. At each of these levels, you can help your child achieve better communication skills by practicing communication whenever you can find time. Make practice a regular part of mealtime, playtime and going about household chores.

One method is called picture communication. The children have certain recognizable pictures that are put together on a pamphlet or board and carried with them at all times. When they wish to communicate an idea or a need they point to the appropriate picture (such as a picture of a drinking glass when they want something to drink).

Another method that is more easily understood by persons not in regular contact with non-verbal children are Bliss symbols. Bliss symbols are a system of lines and dots combined in a certain form to stand for a word. Bliss symbols are paired with their written word and put on pamphlets or boards and carried with the child at all times. Children point to the Bliss symbol to communicate to the person "listening" the word written underneath the symbol. With good teaching and practice some non-verbal children can use over 300 Bliss symbols to communicate.

Sign language is yet another method for communication by the non-verbal children. Sign langauge is the use of gestures, which can communicate one word or a whole sentence, and finger spelling, using fingers to spell words. A non-verbal child can have a very large vocabulary of signs used to communicate with others.

Often with non-verbal children a combination of signing and speech is used. The child may not say the word exactly right, but the combination of speech and sign gets the communication across to the other person. An example is the following diagram from the Glenkirk Association's My Terrific Just for Me Book, a book for parents and interested persons to help teach non-verbal children sixty basic word signs, in total communication format.*



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*With permission of the Glenkirk Press, Glenkirk Association for the Retarded, Northbrook, Illinois.

Helping Your Child to Better Speech

For the verbal child, words are said in hundreds of combinations that are made up not only of word-sounds, but also of melody, pitch, volume, and rhythm. Speech is good and pleasant when all these things work well together and convey an idea.

When children are unable to say the sounds and syllables as they should be said, they have an articulation problem. With an articulation problem sounds are left out (omission errors), are formed poorly (distortion errors), or one sound is made instead of another (substitution errors). Only one or two sounds may be affected or there may be so many articulation errors that the child's speech cannot be understood.

If the words are monotonous, and have no variety or are spoken in tones too high, too sharp, too husky, too hoarse, too nasal, or too soft, it is called a voice problem. Usually these and other similar voice problems are not as serious because children's voices change as they grow older.

If the words come out jerkily instead of smoothly, it is called a rhythm problem. All children hesitate and repeat when speaking, some more than others. Usually, as they grow up, they speak more and more smoothly. Simple hesitating and repeating are not in themselves serious. When the problem is so severe that it interferes with your child using speech without a great deal of effort, as in stuttering, then the child should be examined by a speech and language therapist.

With all language and speech problems the first goal of therapy is to get the child to exchange ideas either verbally or non-verbally. Once the child can exchange ideas, then the speech problems can be worked on.

Here are a few general suggestions to help your child to better speech. Let speech be fun. Let the child know that you like to talk with him or her. What your child says is less important than that he or she enjoys both talking and listening. Play games with sounds and words. Tell stories and read aloud. Build up feelings of success about speech. Do not try to correct every error in grammar. In time the child will correct himself or herself if you set a good example.

Speech and language therapy is offered through the schools. Should you desire therapy outside the school, the Easter Seal Society, as well as speech and hearing clinics and clinicians in private practice can help.

Hearing Problems

For children with hearing problems the Lake-McHenry Regional Program has audiological testing equipment for disabled persons under twenty-one. The Illinois Institute for Developmental Disabilities at 1640 West Roosevelt Road, Chicago, Illinois 60608, has free audiological testing for the developmentally disabled over twenty-one. Should your child have a hearing aid, equipment can be serviced at the centers listed in the phone book yellow pages under "Hearing Aids". For recommendations of dealers and service repair centers ask the school speech and language therapist or the school nurse.

Recommended for Further Reading

Molloy, Julia S. and Arlene Matkin. Your Developmentally Retarded Child Can
1975 Communicate: A Guide for Parents and Teachers in Speech, Language, and Nonverbal Communication. New York: John Day.
Book is organized to progress from the basic principles of speech and other means of communication to specific steps, detailed and understandable, stressing short, practical methods, which can bring definite and observable improvements.

Newcomb, Joyce R. and Carol R. Heitman (illus.). My Terrific Just for Me Book.
1977 Glenview, Illinois: Glenkirk Press.
Utilizes total communication concept to present sixty words selected from a list of words children consistently use first. Teachers and parents can become familiar with the sign and help teach the children. Looseleaf format allows insertion of more signs as the child learns more.

For more information on Speech and Language write to:

The American Speech and Hearing Association (ASHA)
9030 Old Georgetown Road
Washington, D.C. 20014

Special Equipment Repair

If your child uses special equipment (such as walkers, wheelchairs, or leg braces), maintaining that equipment in good repair and getting all the necessary parts when they wear out can be difficult. If your child is enrolled in a special education school, the therapy staff (including the physical and occupational therapists, and the maintenance person) may be equipped to handle breakdowns. Since the staff works with large numbers of children using special equipment, staff members regularly have contact with companies that manufacture and distribute the equipment. Parents of children who are not in the public schools' special education classes, however, find it difficult to find anyone who is knowledgeable and willing to fix the equipment. One suggestion: Contact the special education district and ask for the names of the physical and occupational therapists that the district employs. Call the therapists and ask if they would, for an agreed fee, fix your child's equipment on a regular basis. If they cannot, ask them to recommend someone whom they think may be able to help. Three places to call are the rehabilitation departments of hospitals, long-term care facilities listed in the back of this manual, and companies that manufacture the special equipment. Manufacturers may be able to recommend repairmen.

Nutrition

The cause of many problems associated with developmental disabilities is poor nutrition. Physical complications associated with the disability, and medication regularly taken to control symptoms of the disability, cause problems with eating which in turn cause poor nutrition. Many techniques have been developed for parents to use with their children at home. The techniques range from the adjustment of utensils to suit the abilities of the child to the appropriate timing of medication and meals. Each disability has eating problems associated with it, found in one or more of four areas: inability to suck, chew, and swallow; inability to grasp/poor hand coordination; weight control; and lack of proper nutritional information for parents.

The information and techniques discussed below are only examples of possible solutions to eating problems in the developmentally disabled. To get more information for specific techniques for your child, the physical and occupational therapists, the nurse and the teacher at your child's school can be helpful. If your child is not enrolled, the Lake-McHenry Regional Program, the Glenkirk Association for the Retarded's 0-3 Program, and the Low Incidence Cooperative Agreement (LICA) Program of the Northern Suburban Special Education District (NSSED) could put you in touch with professionals who may be able to help. Of course, your doctor and nutritionist can help.

Sucking, Chewing and Swallowing

The inability to suck, chew, swallow or eat solid foods is associated with many disabilities. Some examples are as follows. Down's Syndrome children have a general delay in their rate of growth which accounts for the delayed appearance of oral reflexes, such as sucking. When teeth start to come in they are often not aligned well (malocclusion) making chewing difficult for both Down's Syndrome children and cerebral palsied children. Uncoordination of lips, tongue and throat muscles make eating very difficult for some cerebral palsied children. Dilantin, taken by some epileptic children, causes gums to swell and become spongy and tender, making chewing painful. Early in life autistic children may show an extreme intolerance to solid foods, with severe gagging and refusal to chew or swallow "junior" foods.

If your child sucks weakly, you can develop a stronger sucking motion. Sweet cold substances are most helpful in stimulating the sucking response. Offer cold water sweetened with honey; dip a Q-tip in fruit and then rub the gums and tongue with it, or place honey or pureed fruit on a pacifier. Children differ, so experiment to find out what kind of nipple suits them. As the child learns to suck better replace the nipples with smaller-holed ones so that sucking will become stronger. Be sure to cuddle and talk to your child.

If your child has trouble swallowing, you can help teach the proper swallowing motion. As your child learns to suck better, the swallowing usually improves. Difficulty in swallowing is often caused by the position of the tongue and the use of the tongue. Your child should take food off a spoon with the upper lip and should close the mouth to swallow. Tilting the head back may seem to help temporarily, but your child will not learn to use the tongue to force food back towards the throat. To help your child swallow, gently stroke the throat upward under the chin or stroke the side of the face from the ear forward to the corner of the mouth.

You can do many things to help your child learn to chew. Your child is ready to chew when he or she can move the tongue and has the main teeth. But the absence of teeth should not prevent an attempt at chewing such foods as crackers, cooked, chopped vegetables or cooked potato. When your child has the primary teeth, place a small piece of food between the back teeth and move the lower jaw up and down. Show your child how you chew, and use a mirror so the child can see how he or she chews. Place the food on alternate sides of the mouth so the child becomes accustomed to chewing on both sides. Give your child bite size pieces of food to start. Introduce lumpy foods gradually. It will be harder for an older child who has eaten only pureed foods to learn to chew than if exercises are begun with the child at an early age.

Help your child become aware of the mouth, tongue, and teeth. Look in the mirror with your child and identify parts of the mouth by playing games and pointing. Do exercises with mouth and tongue in front of the mirror (for example, yawning, kissing, and blowing). Teach your child to move the tongue to touch the upper lips, lower lips and the corners of the mouth. Placing peanut butter or honey at these points will reward your child when using the right movements. Work on this either at the beginning of meals or during special snacks.

Due to painful gums, some children find it hard to progress to solid foods. Pureed foods or strained foods may be necessary at first, but change to coarser foods as soon as possible. A younger child seems to accept these new and strange lumps better than an older child. When your child can control the throat, tongue and mouth muscles, add chopped foods and later solid foods. If the change is gradual your child will become accustomed to the coarser textures, and with practice will learn how to handle these foods. To add more textured foods to the diet use more pulpy drinks such as orange or tomato juice. Add chopped fruit and vegetables to pureed foods. Add bits of crackers and fruit to soups and cereals.

Good dental care will keep teeth strong and may eliminate gum swelling and pain that makes chewing, sucking or swallowing difficult. In addition to toothbrushing and flossing described in this manual's section on Dental Services, you can prevent dental decay by avoiding an excess of foods containing starch and sugar, such as candy, soft drinks, pastries, cookies, and sugar coated cereals. If you do serve sweets, do so with the meal. These foods stick between the teeth or cling to the tooth surfaces where they are rapidly turned into destructive acid by bacteria in the mouth. If served with a meal, other foods will help dislodge sugar from between the teeth.

Grasping and Hand Coordination

The inability to grasp and poor hand-to-mouth coordination are associated with many disabilities. Children with cerebral palsy often find self-feeding to be difficult. If they are athetoid, the excessive movements during eating can cause a great deal of food spillage. If the child is spastic or ataxic, movement is often restricted or limited in the arms making self-feeding difficult. Other children who have motor problems, but are not as severely afflicted, find hand-to-mouth motions very frustrating.

Your child will learn to eat with less effort if the eating utensils are suitable. Instructions for making or improvising special eating equipment should be obtained from your physician, occupational and physical therapists, nurse or nutritionist. All adjustments to eating utensils should be done under their supervision. For example, spoons, forks, knives, and cups may need to be built up with foam curlers or bicycle handles which can be held more easily. Long-handled cups are helpful because the entire fist can be used for grasping. Rubber coated spoons may be used if your child bites the spoon. Plastic dishes are practical and economical since they do not break easily. A plate with built-up sides can be used to help push food onto the fork or spoon.

Encourage children to feed themselves as soon as they show a desire to help themselves. Work toward independent eating. Start by helping children to grasp spoons and cups and to bring food to the mouth. As they learn the movements, help them less. If the abilities to grasp or reach seem weak and uncoordinated think of activities at non-meal times to strengthen and improve coordination. Some examples are pouring sand, playing with a ball, using push-pull toys, and playing in water with a bucket, spoon, and cup.

Weight Control

Weight problems are related to certain disabilities. Down's Syndrome children have lower energy requirements than other children of a comparable age and they can therefore tend to become overweight. The caloric needs of a child with spastic cerebral palsy, where muscles counteract one another making movement very limited, are very small. Being overweight is undesirable because it restricts movement which in turn makes the problem worse. Movement is also limited for children with ataxic cerebral palsy. They often have poor balance, fall frequently and therefore do not move around much. Limited movement means that the child has less need for food than others with greater mobility.

If your child is overweight, you can help him or her to lose weight. Before starting any weight reduction diet, be sure your child has a medical examination to be certain weight loss is advisable. To prevent your child from gaining too much weight, follow a food plan which provides foods from each of the four basic food groups: vegetables and fruits, meat, dairy products, and breads and cereals. For snacks choose foods such as fresh fruits, raw vegetables, nonfat milk, toast with low-calorie jelly,or fruit juice instead of soft drinks, potato chips, and candy. Special diets are available from your doctor and nutritionist.

Proper exercise is important. Encourage your child to take part in activities that strengthen the body and improve skills. There are many games and activities to do at home. Special recreation district programs offer many possibilities for other activities (see section of this manual on Recreation). The recreation specialists at school or at your park district may be able to give you advice on exercises that would be appropriate for your child.

Some children have a tendency to be underweight. Athetoid cerebral palsy involves exaggerated involuntary movements of the arms and legs which makes the caloric need for such a child almost twice that for other children. Some children on medication find that they are not hungry or feel sick after taking their medicine, and do not want to eat. The result is an inability to keep their weight up to normal.

If your child is underweight, there are many ways to help him or her gain weight. Protein foods are essential. Eggs, meat, poultry, fish, beans and milk are some protein foods that can help increase your child's daily calorie intake and provide the nourishment needed for better growth. By increasing the number of meals each day from three to four or more, you may be able to help you child gain weight. Offer snacks often but not "junk" food. Praise your child for good efforts to finish meals. A nutritionist or doctor will help plan a diet that will include more high calorie foods that will be beneficial to your child's growth.

For children who seem to lose their appetite because of the medications that they take, serve the main meal either before the drugs are taken or whenever their effects are expected to be the least. Ask the doctor who prescribed the drugs or the pharmacist about the most appropriate timing for meals and medications.

Proper Nutrition

Lack of proper nutrition information also causes eating problems for children with developmental disabilities. Parents need to know more about good diets to prevent some developmental disabilities, plus correct nutritional advice for the whole family. Two examples of special diets follow, along with some suggestions on making meal time a pleasant experience for your child.

An inborn error of metabolism makes children born with phenylketonuria (PKU) unable to process certain foods which are essential to the child's mental and emotional growth. There is a special diet that must be followed in order for the child to avoid the harmful effects of the disability. Almost all children are tested for PKU at birth. If they are identified as having PKU, they are put on the diet immediately and must adhere to it strictly. Testing shows that children may have to remain on the diet for almost twelve years.

Another diet, introduced by Dr. Benjamin Feingold in 1973, is an additives-free diet, a diet free from such food additives as food colorings, flavorings, and preservatives. It has been credited with lessening hyperactivity in some children. Since the introduction of Feingold's diet, studies have been completed which show that if a relationship exists between diet and behavior (like hyperactivity), it is of relatively minor importance or exists only within a small subpopulation of children. The Feingold Associations sponsor the diet and other information, but it would be helpful to consult others (such as your physician or nutritionist) to find out the latest information on this controversial diet.

Good eating habits and good eating positions are necessary to help make eating enjoyable. Children usually imitate their parents, so set good examples.

There may be days when your child does not feel like eating, or some foods are not appealing. Respect your child's wishes as long as they do not seem excessive. Do not stand over your child to make sure that everything is eaten, because fussing over the child may spoil your child with attention. Mealtime may become a time of pleading, begging, and threatening. If you offer good food in a matter-of-fact way and maintain a pleasant relaxed atmosphere, both of you will enjoy the meal.

An unpleasant experience, such as choking or gagging, may cause a child to dislike or refuse to eat a particular food. For the same reason, unfamiliar foods may be feared or rejected. Many children need to be encouraged to accept new foods or they will continue to eat only those foods which are familiar and easily swallowed.

To introduce new food, serve a small amount along with a favorite food. Do not introduce more than one unfamiliar food at a time. Gradually, your child should begin to accept and to like a varied diet.

A plate heaped with more food than your child can possibly eat is likely to spoil the appetite for the entire meal. Give small servings at first and encourage your child to ask for second helpings.

The information presented here on nutrition is only a beginning. To make sure that your child is getting the best nutrition possible for maximum development and good health, you should ask for advice from your doctor or nutritionist. Also, consult the nurse, physical and occupational therapists, or a teacher at your child's school. Other organizations, such as the Women-Infants-Children (WIC program discussed in this manual's Planning Section) and Expanded Food and Nutrition Education Program (EFNEP) run by the Lake County Cooperative Extension Service 102 South Sheridan Road, Waukegan, phone: 662-4992, offer meal planning information for the whole family.

Recommended for Further Reading

Pipes, Peggy L. Nutrition in Infancy and Childhood. Saint Louis, Missouri:
1977 C.V. Mosby.
Written for health science students, this book includes theoretic nutrition information as well as factors that must be considered when dietary intakes of children, from infancy through adolescence, are being evaluated. The last two chapters deal with nutrition and feeding of children with developmental delays and with behavior management of feeding.

FIFTY EXCUSES FOR A CLOSED MIND

1. We tried that before.
2. Our place is different.
3. It costs too much.
4. That's beyond our responsibility.
5. We're all too busy to do that.
6. That's not my job.
7. It's too radical a change.
8. We don't have the time.
9. Not enough help.
10. That will obsolete our equipment.
11. Our organization is too small.
12. Not practical for busy people.
13. The students will never buy it.
14. We've never done it before.
15. It's against school policy.
16. Runs up our overhead.
17. We don't have the authority.
18. That's too ivory tower.
19. We did all right without it.
20. That's what to expect from staff.
21. It's never been tried before.
22. Let's form a committee.
23. Has anyone else tried it?
24. I don't see the connection.
25. It won't work.
26. Let's get back to reality.
27. That's not our problem.
28. Why? It's still working today.
29. I don't like the idea.
30. You're right - but ---.
31. You're two years ahead.
32. We're not ready for that.
33. We don't have equipment or room.
34. We don't have personnel.
35. It isn't in the budget.
36. Can't teach an old dog new tricks.
37. Good thought but impractical.
38. Let's hold it in abeyance.
39. Let's give it more thought.
40. Put it in writing.
41. They'll laugh at us.
42. Not that again.
43. Where'd you dig that one up?
44. What you're really saying is...
45. In your department, yes, mine, no.
46. Let's all sleep on it.
47. I know a fellow who tried it.
48. Too much trouble to change.
49. We've always done it this way.
50. It's impossible.

Family Counseling

When a baby is expected, the family is usually excited. Parents think of names, tell friends, get a room ready, and do other things to express their joy. Some parents, wanting to learn more about babies, read books (like Benjamin Spock's Baby and Child Care) or seek other information. But no matter how much parents want the baby, or how much they have read, there are some things they are not prepared for. Knowing that babies cry is not the same as having to stay up all night with a crying baby. The arrival of a baby changes the parents' lifestyles; even a trip to the grocery store can become troublesome if the baby has to be brought along. The baby might also affect relationships within the family. For instance, a husband or other children might become jealous of all the attention the baby receives. There are more little things that parents do not find out until the baby is acutally born. These little things bring a degree of harshness into the wonderful world the parents expected. Of course, this does not mean that they love the baby less.

If you consider how much frustration average parents feel when their cherished dream has to be given up, then the negative reactions of parents of a child with developmental disabilities are understandable. Besides dealing with unexpected things that all parents encounter, they have to cope with special considerations, too. It is hard for parents of a new-born child with developmental disabilities to carry out everyday activities like going to work and taking care of the house when they are so emotionally confused that it is difficult to function.

Every parent has individual reactions, but there are some common responses, too. Ken Moses, a North Shore psychologist, says most parents go through five states in the grieving process. The first state is DENIAL. In this state parents, who knew nothing about the disability before the child was born, refuse to accept its impact or irreversibility. Education helps parents to understand; as they get more information from doctors and other parents about their situation, they will probably come to accept it more.

The second state is GUILT. Parents might wonder if the disability is a punishment for something they have done in the past. Sometimes they think the disability was caused by something they did or something that happened to them. They may ask a doctor for a medical explanation. If their questions are spiritual, they may consult a clergyman. In fact, the Waukegan Developmental Center includes a chaplain on its staff.

In the third state, DEPRESSION, parents are punishing themselves. They are unable to admit that they are basically good people, trying their best to help their child. Parents might take out their frustrations on themselves, through overeating, drinking or relying on medication such as prescription drugs.

ANGER is the fourth state. Scapegoating can occur, where frustrations are taken out on an innocent person, such as a husband, wife or child.

Harming another or oneself, or even being afraid of hurting someone, is not uncommon, and it occurs in families without developmentally disabled children, too. In the Chicago area there is a Parental Stress Service hotline (312-463-0390), that you can call 24 hours a day. They will listen if you want to talk, and if you need further assistance they can refer you to other sources. You should not be ashamed to admit that you are upset; anger happens to everyone at times, and stored anger is more harmful than frustrations that are slowly released.

The fifth and final state is BARGAINING. Parents still retain a hope that if they make more sacrifices (for example more time, more money) the disability will be removed.

The grieving process ends when parents replace their fantasies with realistic hopes and expectations. They accept the child as a person and want to help the child achieve the highest potential possible, whatever it may be.

This is an exhausting process for parents to go through. It is a lot easier for parents who have support. Support can simply be a good friend's shoulder to lean on or an ear to listen.

If you are going through a grieving process, good friends can help you get your strength back in the short run. But, because they do not have developmentally disabled children themselves, you may feel they cannot fully understand what you are going through. That is why you may want to join a parents' group associated with your child's school. Parents of older developmentally disabled children have had many of the experiences you are encountering, so they can coach you through them. They try to answer questions you may have about everyday life, like where to find a baby-sitter, or questions about your own behavior toward your child. Sometimes you may wonder, for example, if anyone else besides you gets upset at small disasters, such as milk spilling. Parents who have coped with the situation longer than you, will reassure you that becoming angry does happen.

However, your concerns might deal with things other than getting through every day. You may be planning the future of your child, and looking at educational and residential choices. You may wonder about the intelligence level and potential ability of the child. There are people in the school who can help you with these concerns, like a teacher, nurse or social worker. Besides having experience in working with many developmentally disabled children and being informed about resources in the area, they personally know your child. You might want to speak to them about some of the hopes and frustrations you feel as well as discussing these concerns in parent groups.

School personnel vary in their willingness to speak with parents. Some may consider it part of their job, while others may charge a fee for prolonged individual consultation. Social workers are usually sources of information for future plans, and many run short workshops for parents' groups. In fact, one purpose of school personnel is to provide you with resources. Any decisions that you make should be yours alone, based in part on what they have told you. Do not let them pressure you into making a decision because of an opinion they may express.

While it is important to stay in contact with you child's school, you may prefer to speak about your feelings with professional counselors. The advantage of consulting professional counselors is that you see them only during your appointments; you do not socialize with them as you might with parents of other developmentally disabled children, and you do not see them when you pick up the child from school. The relationship ends when you leave the office (or when they leave your home) and you know they will not talk about you with outsiders.

There are a few things to keep in mind if you are considering speaking to a professional counselor. First, there may be a fee. The range is anywhere from no charge to $50 per session. Some places charge a per session rate, while others charge by the week or for a group session meeting over several weeks. You should ask how much it will cost and how long it will take when you make the appointment. Another thing to remember is that Illinois has no qualifying regulations for counselors. Anyone can call himself or herself a family counselor. A good place to start with is with people who have experience in helping situations, like clergymen, psychiatrists, nurses, and social workers, who may offer their services. There are lists in the Yellow Pages of the Telephone Directory under "Marriage and Family Counselors", "Psychologists", "Clinics", and similar titles. You may feel more confident asking your family doctor or school personnel for a reference.

When you make the appointment,ask about fees and how long the session will take, but also ask what information you should bring. Often the first session is a "getting acquainted" time, so you should prepare a family history and attempt to put things you want to discuss into words, like frustrations or future plans. Remember that you are also getting to know the counselor. If you feel uncomfortable, you might wish to seek another. You are there for help; do not be afraid to interrupt or ask questions. If you do not feel that the counselor is responsive to your needs, then do not waste your time or money by continuing to consult him or her.

It is difficult to tell exactly what will occur during the consultations. It depends partly on you and your needs, and partly on the philosophy of the counselor. It is very common for the counselor to request that the entire family be present. Sometimes the counselor might want to spend some extra time with the other children by themselves, if there are any, and sometimes with only one of the parents. Generally, though, the counselor likes to get some sense of the "whole picture". In fact, sometimes sessions might be held in your home instead of in the counselor's office.

Each counselor takes a different approach in the therapy. When you think of therapy you may envision the stereotyped psychiatrist-and-couch type of consultation, and indeed, that sometimes does occur. More common is the conversation-like therapy where clients and counselor sit in chairs facing each other. Sometimes the counselor may suggest that you reenact a particular scene that disturbs you or that the husband pretend to take the wife's role and the wife take the husband's role in a specific situation.

The focus of therapy is determined by the counselor. Some counselors believe that you should work out immediate everyday problems first, while others prefer to work on improving the circumstances around your concerns. Still others may begin by concentrating on your past.

When you speak to a counselor, the two of you will probably draw up goals together. One goal might be to get through every day by understanding the needs of each family member. Another might be to make a decision about the placement of the child. Yet another might be how to help the child reach full potential. In this last case, you might be learning specific techniques (such as toilet-training) to practice at home.

Once you have begun to understand yourself from your work with the counselor, then you can begin to make decisions about the future of your disabled child. After discussing realistic expectations you should have of the child, you can begin to plan your child's activities and education. If you decide to care for your child at home, you will have the information and resources to support you. If home care is planned, you might want to take advantage of the filmstrips and other "how to" media offered by the national organizations concerned with developmental disabilities. They are listed in the directory. You will probably find yourself becoming involved in some activity designed to educate the public so that community attitudes are more accepting of persons with handicapping conditions. If your final decision is to place the child in residential care, you will know that you have explored the options with the experts and chosen the best place for your child.

Recommended for Further Reading

Noland, Robert L. Counseling Parents of the Mentally Retarded. Springfield, 1970 Illinois: Charles C. Thomas.
A six-part book presenting information specifically directed at the counseling of parents of the mentally retarded. Section 1, articles designed to provide an overall orientation; (2) initial informing interview with parents; (3) group counseling; (4) family casework and child placement; (5) pastoral counseling; (6) genetic counseling.

Schrieber, Meyer, and Mary Feely. Siblings of the Retarded. Available from the National Association for Retarded Citizens, P.O. Box 6109, 2709 Avenue E East, Arlington, Texas 76011.
Report on group sessions done with adolescent siblings of handicapped youngsters in New York City.

Recreation

Few groups have more leisure time than the developmentally disabled. Their free time has been forced upon them because of their disability and lack of planned opportunities for both work and play. Leisure time is an important part of their lives. Learning how to plan and use leisure time effectively can mean the difference between a boring, sedentary life and an active life of increased fitness and sharpened artistic, recreational, and social skills.

Family Activities

The home is the ideal place for learning to use leisure time effectively. Through family recreational activities, the child with developmental disabilities will learn the value of constructive use of leisure time. The activities that the child enjoys and does well in will become life-long hobbies and can turn into vocations when the child reaches adulthood. For example, a hobby such as gardening, can turn into a job in a nursery. Some of the national parent organizations put out pamphlets and booklets on activities that families can do together with their handicapped child.

With the proper supervision and training, most children with handicaps can achieve a level of competence in some activities. In activities that the family does together (for example, gardening, swimming, golf, volleyball, bowling, camping, working on cars, fishing or ice skating) the child can be taught the basic skills in small steps. For example, instead of teaching the handicapped child how to garden and asking the child to take care of a small garden, there are several steps that can be taken. First, teach the child how to use some of the gardening tools. Then instruct the child about proper watering and weeding techniques. Use the child as a helper in doing the family garden. When the child has learned enough skills, allow the child to have a gardening spot. Although this may take a few months of the whole growing season, the child will be able to care for growing things indoors and outdoors all year. When the child grows older and may live away from home, surroundings can be brightened with flowers and plants.

In addition to the many sports, games, and other recreational activities that a child can learn to enjoy, it would be beneficial to set up a daily routine of exercise. These exercises can be obtained by contacting the physical education teacher at your child's school. The exercise program should start with a very light load and increases gradually over a period of time. Recommendations on kinds and duration of exercise should be made by your family doctor or by the physical therapist at the school, if your child sees one.

Helpful ideas and training techniques for different recreational activities can be obtained from a variety of public and private programs that specialize in recreation for the handicapped. They offer specialized activities for handicapped children and their families that you may find useful in helping your child to use leisure time effectively. They do charge for their activities, but you may find the costs reasonable when you realize the enjoyment and skills your child may obtain from participating in the activities.

Special Recreation

The widest selection of recreational programs is usually available through the park districts. Not every community in Lake County is included in a special recreation association, but most are. The table at the end of this Chapter lists the towns served by the three special recreation associations in Lake County.

Most of the special recreation associations offer recreation classes in four areas: arts and crafts, sports, social clubs, and special events (for example, summer camps, holiday parties, and overnight camping). Arts and crafts activities include woodworking, photography, dance, music or other kinds of self-expression. Swimming, gymnastics, ice skating, tennis, basketball, and bowling are but a few of the sports that programs offer. Special training techniques have been developed that make almost any sport adaptable to your child's specific abilities. Social clubs are a good way for your child to socialize with others and make friends. Activities are held at the public recreation centers or the teens and young adults go out to movies, plays, professional sport games or dances. Special events provide the opportunity for your child to have experiences that otherwise might be missed. In addition to holiday parties, most of the special recreation associations offer chances for overnight camping and some offer residential summer camps that last from a few days to two weeks.

Costs for activities differ at each recreational association and for each program. If your town's park district is a member of a special recreation association, the costs for the programs are quite reasonable. Some of the recreation districts have reciprocal agreements with other districts so that if your district does not provide a certain activity but another one does, you might be able to enroll in that course without paying the out-of-district fee. Check with your special recreation department. Arrangements may be made with the special recreation districts for scholarships or reduced payments on a case-by-case basis.

If you live outside the special recreation districts you may have to pay an out-of-district fee for each class in which your child is enrolled. If your park district is not a member of a special recreation district, encourage it to join. If it receives federal funds it is obligated to provide recreation programs for the total population.

Private Programs

Private facilities also provide special recreation for the handicapped. Many scout troops are organized through the schools and consist of after-school meeting and activities. Your child may be able to enroll through the regular scouting channels or there may be a scout troop for handicapped children at the school your child attends. Scouting often involves parents as troop leaders and assistants. Scouting is a good means of doing an activity with your child outside of home. If you are unable to find a scouting troop in your area to suit your needs, the councils listed in the back of this manual will help you start a troop in your child's school or through your church or neighborhood organization. Call your local council if you are interested.

The YMCA's and the YWCA's often offer some courses especially tailored to handicapped people. Check with your local chapters listed in the back of this manual. Most chapters will help you if they do not already have programs for the handicapped.

There are three interesting programs that are exclusively for handicapped people. One is called Friends of Handicapped Riders (FHR). The FHR offers horseback riding as therapy primarily for physically handicapped children, but will take children with other disabilities, too. Research has shown that horseback riding increases balance and coordination in children who have physical disabilities. Some special recreation districts have horseback riding programs through FHR stables. If your district does not, you can arrange to have your child enrolled without sponsorship by the special recreation association.

Another interesting recreational program is the Center for Enriched Living, which provides recreation and social interaction for mildly and moderately retarded adults. The classes in the special recreation districts are often geared toward school-age children, though more are now becoming aware of the needs of handicapped adults for recreation and social activities. The Center for Enriched Living fills this void.

Gardening can be a life-long hobby as well as a viable vocation. With very little expense and minimal skills, children with developmental disabilities can start growing and planting flowers and foods. The Botanical Gardens of the Chicago Horticultural Society offer guided tours and classes on the different aspects of outdoor gardening. With your child you can start an outdoor garden for the summer and maintain growing plants indoors year-round.

Summer Programs

Summertime brings a one- to three-month break in your child's school year. Summer is a good time for you and your child to have a vacation from one another. Many organizations sponsor summer residential and day camps for children with handicaps. The application process starts in the spring, but some camps begin to accept reservations at the end of the summer for the next summer. Your special recreation association may sponsor both a day camp and a residential camp, so check with it. Easter Seals, the Illinois Association for Retarded Citizens, and the National Society for Autistic Children publish listings of summer camps in Illinois and across the nation. If you wish to organize your own group of campers for a summer camping trip, or even for a spring or fall weekend, many camps rent their facilities for school and church groups.

Recommended for Further Reading

Coxon, Margaret E., Gardening as Therapy. Technical Bulletin No. 5, 1978 available from office of The Botanical Garden, 6501 N. W. Marine Drive, The University of British Columbia, Vancouver, British Columbia, Canada V6T 1W5 for $4.25 + postage.

A teaching guide designed to help parents and teachers who are not plant experts prepare a plant class for developmentally disabled children. Ten chapters each contain a complete project for springtime gardening. Good illustrations. Other volumes may follow.

Special Recreation Associations:
Participating Towns of Lake County

Northeastern Illinois Special Recreation Association (NISRA)
- Libertyville
- Mundelein
- North Chicago
- Waukegan
- Zion

Northern Suburban Special Recreation Association (NSSRA)
- Deerfield
- Highland Park
- Highwood
- Lake Bluff

Northern Illinois Special Recreation Association (NISRA)
- Barrington

Community Services

There are dozens of social service agencies and clinics, religious groups, colleges, medical facilities, service organizations, libraries, state offices, and informal networks. Many provide services to support families with developmentally disabled children.

Since almost all community services are plagued by a high staff turnover, the first person you contact may not be well informed. Keep a record of all contacts by date, name of agency and persons consulted, and information received. This can help you later if you are refered back to the agency. Consider yourself very lucky if a single telephone call brings you the help you need. Often, in fact, it is preferable to check out alternatives to make sure you have found the best answer for your particular needs. (See the Chapter on "Parents of Children in Programs" for beginning leads to selecting programs.)

Only you know if you are getting the kind of help you need. If you are not satisfied, ask to talk to somebody else. Be sure to get a referral from those who are unable to help you. Keep asking people in a variety of settings, such as parent organizations and schools.

Referral Services

Some organizations, such as United Way, the Epilepsy Foundation of America and Catholic Charities, specifically provide information and referral as part of their services offered. If you talk to a person who cannot help you, in these or other agencies, ask that person to check the Human Services for Lake County People directory published by the Lake County Comprehensive Employment and Training Act (CETA) Program.

A new service being provided around the state is the Family Support Unit. (The one in Lake County is located at Countryside.) Family Support Units are envisioned as becoming the focal point for all developmental disability services and programs related to family, independent living and the community. Their goals include identifying existing resources in the community. Where unmet needs are identified Family Support Units should undertake the development of resources.

Telephone hotlines can be helpful in times of crises. For example, Connection, a telephone counseling and referral agency in Libertyville, provides information to all people in any type of crisis. You will undoubtedly learn about other crisis referral telephone numbers. Keep these numbers by your telephone should an emergency arise.

Child Care and Companionship

Finding a sitter you can trust can be difficult for anyone.

The special needs of your developmentally disabled child may pose additional problems. If you are fortunate, family members, relatives and friends may be available to assist you. There may be a time, however, when outside assistance is needed or wanted. There are persons who are trained to work with children with developmental disabilities, for example, volunteers and employees in special education schools, special recreation programs, and special religious education programs. College and high school students may want to help. Contact service organizations and student governments; put notices on bulletin boards.

Respite Care

Respite care is short term care of the developmentally disabled infant, child or adult. Respite care can be helpful if you are planning a vacation, find yourself in a crisis situation, or just need a break from the daily stress of caring for your family. Respite care is one of the largest unmet service needs at this time. You can organize to help the Family Support Unit make this service a reality throughout the county.

There is a respite care program available through the Glenkirk Association for the Retarded in Glenview, Cook County. Respite care specialists are certified and trained to care for your developmentally disabled child in your own home. In-home service is available for less than 24 hours or for a period up to two weeks. Licensed respite homes are available if you need to have your child taken care of outside your home on a short-term basis.

Homemaker/Home-health Aides

It is easy to overestimate your own abilities to manage everything all of the time. You may need help with managing your household and caring for your family, especially if one of you becomes sick. The Community Health Nursing Services of the Lake County Health Department offer home visits for family-centered health counseling and guidance, including service to expectant mothers, newborns, preschool and school-aged children. Also within the Lake County Health Department, Home Health Services provide nursing, therapy, and home-health aide services. Some hospitals and private agencies offer similar services. Check around in advance.

It is much more difficult to find community support for homemaker services. Most people who need help with their housekeeping tasks pay for it privately. Informal arrangements with other parents can be worked out on a short- or long-term basis. For example, you might exchange baby-sitting services or get together to help each other do housework or home maintenance repairs. Local service agencies may be able to locate a person to help you out. If you are unable to get information on homemakers locally contact: National Council for Homemaker - Health Aide Services, Inc., 67 Irving Place, New York, N.Y. 10003.

Your Child and the Law

The best time to introduce your children to the police is while they are young. Many police departments have "Officer Friendly" programs designed to acquaint children with police work. As your child grows older, he or she should be encouraged to travel independently in your neighborhood and community. This can be scary for parents, but you will impede your child's development if you are overprotective. It will be reassuring for your child and yourself if a good relationship with the police has already been established.

Developing good relationships with the police is a two-way street and this is where your parents' organization can be effective. Police officers need to be familiarized with the special needs of the developmentally disabled, and joint meetings can be arranged for this purpose. For example, a person with cerebral palsy may appear to be drunk and disorderly. It is not necessary to call an ambulance every time a person with epilepsy has a seizure; instead, with training for seizure treatment the option for rest without hazard can be provided. There must be consistency in holding persons with mental retardation accountable. Mischievous (turning in false fire alarms) and more serious (shoplifting) infractions may be committed as attention-seeking devices or through poor judgment. Such violations cannot be ignored, nor will either the person or the community benefit if treated too harshly.

Transportation

The Regional Transportation Authority offers a reduced fare program for handicapped persons. Eligibility forms must be completed by the applicant along with a physician or psychologist.

To maximize your child's self-sufficiency begin training to use public transportation as early as possible. Leave your car at home for some of your regular shopping trips.

Financial Planning

Finances are a major concern of most families and the special needs of a developmentally disabled child may make the burden even greater. Careful planning combined with government and private services can make the expenses of raising your child no greater than those for raising any other child.

Health Insurance

One of the major financial supports is adequate health insurance coverage. National and state parents' organizations for the developmentally disabled (for example, the Illinois Association for Retarded Citizens) have information about the insurance companies and the Blue Cross - Blue Shield organizations which will consider applications on developmentally disabled persons. Review your policies at regular intervals -- at least every five years -- preferably with an insurance agent regarding length of time, amount of allowable coverage, deductions, special exclusions, and renewal or cancellation provisions, particularly if you might have to change jobs.

You are fortunate if your family is already covered by a family plan or a group policy provided by your employer. Illinois has laws which require that the health insurance coverage of any child who is included in a family plan or group contract, and who became permanently dependent on account of a disablement which began before age 19, must be continued under the family plan or group contract after the age of 19. However, you must notify the insurance company or Blue Cross - Blue Shield organization prior to the time your child becomes 19 (some contracts allow a 31-day grace period for such notification.)

Governmental Benefits

Public programs are always in a state of flux. Provisions for the developmentally disabled change often and even the people administering the funds at a local level may not be up-to-date. Verify all information with the district and state offices of the Social Security Administration and local and state parents' organizations for the developmentally disabled.

Most developmentally disabled persons are potentially eligible for benefits under "social insurance" or "income maintenance" federal or state programs. For example, if you have paid "FICA" taxes, your dependent children are entitled to Social Security benefits if your employment is interrupted by retirement, disability or death. Public assistance programs, on the other hand, are supported by general tax revenues; they do not require you to have paid premiums but their availability is determined by family income. For example, the Supplemental Security Income (SSI) program complements Social Security for those who do not have a lot of money (low income, high medical bills, few assets like savings accounts).

In considering the significance of Social Security and SSI, related benefits should also be noted. For example, Social Security brings Medicare (after two years) for all disabled beneficiaries, and SSI recipients may be eligible for medical assistance, for certain housing subsidies, and for a wide range of free social services. Careful planning to combine these different resources may permit a developmentally disabled individual to live at home or in a supervised group home or apartment which is not classed as an institution but which provides some degree of guidance and protection, while also permitting some gainful employment and increased community participation.

Coordinating Planning

The parent with foresight will, while planning, assemble records and information. Such records become cumulative for obtaining additional services and benefits.

The following information with respect to the developmentally disabled person should be kept on hand:

-Social security number (advisable to obtain now, if not already assigned);

-Telephone number of Social Security district office;

-Birth certificate of the retarded person;

-Names and addresses of doctors, clinics, schools, etc., holding records relative to the history of the disability of the individual;

-Last federal income tax return and W-2 statement of the parents (to show coverage under Social Security);

-Veteran's C number or discharge papers of parent;

-Information about present and future income and assets of the developmentally disabled person, including income from trusts, also income and assets of the surviving parent if SSI is to be sought for a minor child;

-Information about SSI if currently being received. Specifically, what is the basis for the amount being received in terms of "countable" and disregarded income, and the type of living arrangement. (A copy of the most recent application form would be useful.)

-Copies of pamphlets and other literature with up-to-date information about services and benefits.

These records should also include copies of guardianship papers, trusts and wills concerning the developmentally disabled person. This information will help secure future benefits for your child upon your death.

Guardianships

In Illinois, parents have responsibility for their children until the children reach eighteen years. But developmentally disabled children sometimes need protection long after they reach eighteen. For this reason, you may want to make arrangements to be sure that your child continues to have someone responsible for him or her.

Developmentally disabled people over eighteen years have the same civil and legal rights, responsibilities and protections as any other citizens. They may vote, marry, choose where they want to live, write a will, buy or sell property, be insured, and even own credit cards without the approval of their parents.

Any or all of these rights may be taken from them, however, through court action. If a court decision determines that a person is legally incompetent to manage certain affairs, the court may appoint a guardian.

Courts appoint guardians most often when disabled people reach eighteen years and are no longer under their parents' jurisdiction. The parents themselves, the court or any citizen may petition for the appointment of a guardian. Once a petition is submitted to the court, guardianship proceedings begin. If the person for whom a guardian is sought lives in Lake County, the proceedings must begin within the county.

The court may appoint a parent or another family member as the developmentally disabled person's guardian. The guardian is responsible for protecting the person's interests while maximizing the person's freedom. For this reason, you will want your child to have a guardian who cares about the child's interests. The guardian should know the child, know about the child's disability, be mature and responsible, and be willing to take an active role in guaranteeing the rights of your child. Your child will be the guardian's ward.

Illinois courts appoint two different types of guardians. The first, a conservator of the person, enters into contracts on behalf of your child. The second, a conservator of the estate, has broader authority. The estate conservator manages the income, expenditures, property, insurance and government benefits, and other financial aspects of the ward's estate.

A guardianship is the traditional way to provide protection for a disabled person older than eighteen, but it can have many disadvantages. For example, to appoint a conservator of the estate will indeed allow parents to provide for the security of their child, but the conservator must go through expensive court proceedings to get approval for many financial transactions. If the parents die, no law prevents a guardian from mismanaging the ward's affairs, and no agencies require a systematic review of how well a private guardian carries out designated responsibilities. (You do have some assurance that the guardian will manage funds properly, however, because court approval is required and because the guardian must give the court an annual accounting.) Court-appointed guardians also charge annual fees that can be expensive. These drawbacks make guardianship an undesirable choice for many parents.

Amendments to a state law that took effect January 1, 1979, established what parents of disabled children have wanted for a long time: limited guardianships. A limited guardian, unlike a full guardian, has control over only those affairs which the probate court assigns. This means disabled persons can continue to make simple decisions on their own, but the guardian will handle complex decisions such as those involving large amounts of money. Unlike a full guardianship, a limited guardianship does not require that the ward be found legally incompetent. A guardian is prohibited from putting the ward in residential care unless the court specifically allows it. The law does not change the status of full guardians appointed before the law took effect, but you can seek to have an existing full guardianship reduced to a limited one by requesting the court to review the case.

The law also authorized the appointment of a state guardian to assume responsibility for the guardianship of disabled people without relatives or whose relatives have no funds to establish a guardianship. As of this writing, however, the state legislature has not provided money to appoint a guardian and run the office.

Because of the cost and the red tape involved in establishing guardianships, many developmentally disabled adults have no guardians, and consequently have no one else to assume responsibility when important decisions have to be made. Nevertheless, if disabled children have made it to their eighteenth birthday without having guardians, they probably can continue in life without guardians, as long as other help and supervision continue.

Trusts

If you want to make provisions to protect your child without a guardianship, consider a trust. A trust is the nominal ownership of property to administer for someone else's benefit. Parents sometimes set up trusts to support their child after they die. Unlike a guardianship, a trust is relatively flexible. A trustee does not require a court order to act.

If you decide to set up a trust, you can fund it with cash, property, and/or life insurance proceeds. You should select a trustee who knows about investment policies, who knows the child, who can serve the duration of the trust if possible, and who can manage the assets in the trust. You may designate a bank or trust company as trustee, but if you do, you may want to designate a person as co-trustee to make sure the institution's fees and performance remain satisfactory after you die.

If you establish a life insurance trust with a bank as the trustee, the bank will collect and invest the proceeds of the policy when the insured parent dies. The bank will pay out money for your child's benefit according to the directions you give in the trust provisions. You make the life insurance payable to the bank, not to your child. For an annual fee, the bank will administer the trust for your child.

You may establish another kind of trust, a testamentary one. This is a trust that is set up according to directions in a will. A will is a legal document specifying what part of the money and other things you own will go to whom after you die. A testamentary trust begins when the will takes effect. You may indicate in your will the person(s) or institution(s) you want to serve as your child's trustee(s) after you die. The trustee will report regularly to the probate court.

If you prefer, you may also use the will to set up a guardianship instead of a trust. Such a guardianship, of course, will have the same advantages and disadvantages described in the above paragraphs on guardianships.

Wills

You should write a will whether or not you intend to establish a guardianship or a trust. If you do not write a will, your property will pass on to your heirs under Illinois law, whose provisions are not designed for families with handicapped children. Your child may not receive the best protection you can provide.

You should have legal assistance to establish a guardianship, trust, or to make a will. If you cannot afford a private lawyer, you may be able to get help from one of the legal service agencies listed in the back of this manual.

After you write a will, review it at least every five years to make sure it still meets your requirements.

A Word of Caution

Before you decide to establish a guardianship, trust, or to make a will you should carefully consider the needs of all your family members. You may not wish to establish a trust fund for your developmentally disabled child at the expense of current family needs, for example. Supplemental Security Income (SSI), Medicaid, and other programs are designed to provide for handicapped persons. Yet your child can be declared ineligible for these funds until personal funds (such as trust monies) are exhausted. Many parents have been sorry they created trusts for this reason, especially when investing in the trust created a family hardship for years.

Some Considerations About Having More Children

As the parent of a developmentally disabled child, you may be considering having more children, and wondering what the chances are that another child could be developmentally disabled. If you are the brother or sister of a developmentally disabled person, you are faced with the legitimate questions about the possibility of your children being developmentally disabled. This is certainly a serious consideration. Medical specialists using modern techniques can help you determine with some degree of accuracy what the chances are that your next child will be normal.

Genetic Counseling

The first step to take when you are considering having more children is to see a genetic counselor at one of the three hospitals close to Lake County that offer genetic counseling (Evanston Hospital, Lutheran General in Park Ridge, and Rockford Memorial). The evaluation is usually done by a team of professionals consisting of a geneticist (a medical doctor who specializes in genetics), researchers, laboratory technicians, and social workers.

Several visits for interviews and testing will probably be needed to complete the process of genetic counseling. At the first interview, you will be asked to provide a complete medical and family history. This will include information on ethnic background, previous pregnancies, and health information about your children, as well as your brothers, sisters, parents and grandparents.

The counselor will be interested in any diseases that are common to either of your families. There are some rare hereditary diseases associated with specific ethnic groups. Sickle cell anemia, an inherited blood defect, is found primarily in blacks, Tay Sachs disease primarily in Jewish Ashkenazic families, and phenylketonuria (PKU), a biochemical disorder, primarily in whites. These are some of the more severe hereditary disorders that genetic counseling can predict.

More common troubles may also be hereditary. High blood pressure, diabetes, and congenital bone defects (for example, hip problems) are common hereditary disorders.

There are just a few examples of the more than 200 hereditary disorders that genetic counseling can predict. Knowing the probable genetic make-up of your future child will help the doctors to monitor your child's growth during pregnancy and after birth. With this foreknowledge, you and your doctor can help the future child to a safe and healthy life.

After providing the medical history, both parents will then be given blood tests and other biochemical tests to determine if either is a carrier of potentially harmful hereditary traits or diseases. When the interviewing and testing is done, the genetic counselors will discuss the hereditary risks of having another child. It is not always possible to tell if a particular disorder will be passed on to future children, but the counselors can advise you on the mathematical chances of certain types of problems being passed on. They will also help you to interpret what these mathematical probabilities mean.

In the end, the decision is up to you. For some, just knowing the odds is reassurance enough. You can take a risk and be prepared, if necessary, to have a child with developmental disabilities. It is wise to be informed before making a decision. Help in this decision could come from other family members or through professional counseling (see section on family counseling).

During Pregnancy

Should you become pregnant there are more options you should know about to determine if your baby will be developmentally disabled or not. There is a positive course of action that you may take that will help your chances for having a normal, healthy baby. This section will introduce you to the medical technology that is available for prenatal examinations. It will also guide you toward good nutrition and health by recommending proper foods and exercise and by discouraging consumption of harmful foods and drugs.

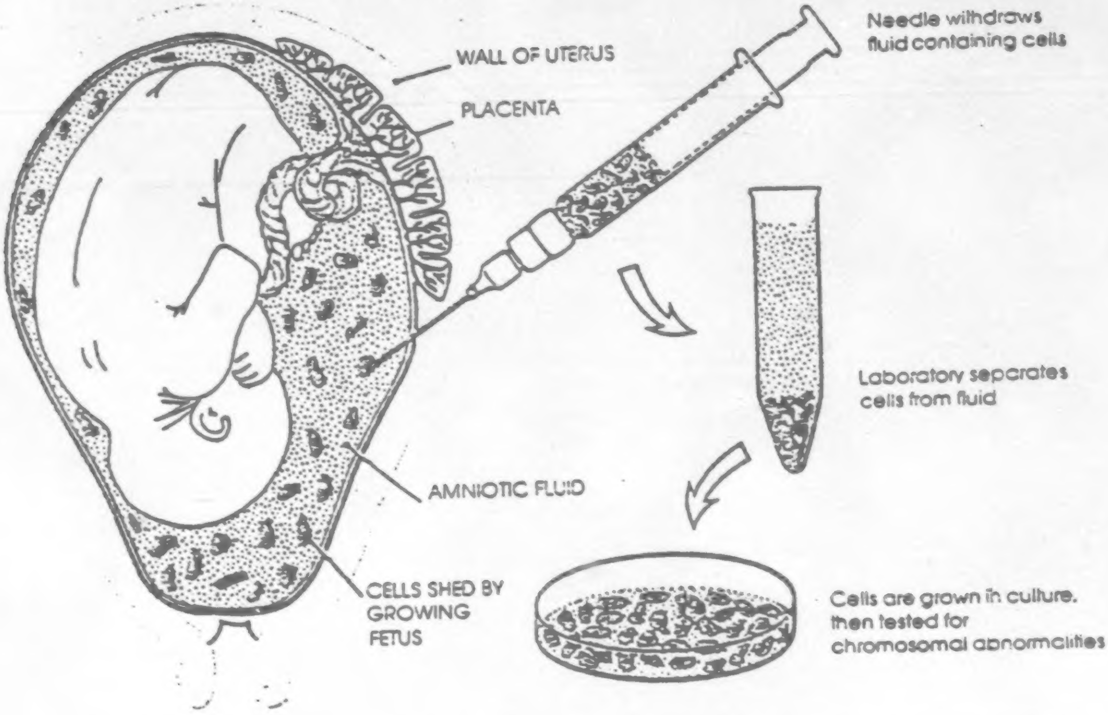
Medical Procedures

There are two basic means of examining the fetus (unborn child in the mother's uterus). Amniocentesis is a minor surgical procedure in which a small sample of fluid in the amniotic sac (the thin-walled covering surrounding the fetus) is withdrawn. The sample is analyzed in the laboratory to determine if some genetic or biochemical disorder is present. See diagram of step-by-step procedure on the following page.

Amniocentesis is done about the fourteenth week of pregnancy. It requires a hospital stay of only a few hours in most cases. A local anesthetic is given, and the woman should only feel slight discomfort. There are some risks in the procedure. Your obstetrician should be able to discuss them with you.

Amniocentesis can pinpoint certain diseases in the unborn child, yet its scope is limited. Examination of the fluid sample can indicate the presence of Down's Syndrome, Tay Sach's Disease, or other genetic disorders. An analysis that shows no known chromosomal or biochemical disorders, however, does not give a 100% assurance that your child will not have a developmental disability. Your child could still develop some other kind of problem or have a condition not detectable by amniocentesis. But an amniocentesis that shows no known disabilities does eliminate the possibility of certain disabilities.

The amniocentesis procedure, step by step



Needle withdraws fluid containing cells

Laboratory separates cells from fluid

Cells are grown in culture, then tested for chromosomal abnormalities

Should the amniocentesis indicate that there is a strong possibility that your child will be developmentally disabled, the choices left to you range from taking the risk and preparing for the child's potential needs or terminating the pregnancy.

The second means of detecting handicaps of the fetus is ultrasonography. The technique, which is safe as far as is known involves the passage of high frequency sound waves through the womb. The waves can be transmitted into a picture of the developing fetus. The head size can be measured enabling diagnosis of a gross brain defect, such as a very large or small head. Repeated ultrasound testing every few weeks logs the development of the fetus' head and other body parts, since some disorders are associated with poor fetal growth. Ultrasonography can also be used before amniocentesis to locate the position of the fetus and minimize any danger of injuring the fetus during amniocentesis.

In the experimental stage are two methods for prenatal diagnosis: amniography and fetoscopy. Amniography involves the insertion of a dye into the amniotic sac to outline the fetus when x-rays are taken. More promising, because it does not involve use of potentially harmful x-rays, is fetoscopy. This procedure involves looking directly at the fetus by using a telescope-like instrument. These techniques are only experimental, but in the future may make predictions of disorders more accurate and help find ways of treating children before birth. With all these procedures, there are certain risks. The choice of whether or not you should have these procedures done is up to you. You can say, "No".

Nutrition

You can have a positive effect on the health and well-being of your unborn child by eating the proper foods, avoiding all drugs if possible, and staying healthy by avoiding some common diseases.

During the past twenty-five years researchers have found that proper nutrition during pregnancy will reduce the number of low birthweight babies (babies weighing less than 5.5 pounds at birth). Low birthweight has been conclusively linked with babies having developmental disabilities. Not all low-birthweight babies are handicapped but three times more brain damage is found in infants with low birthweight than in average birthweight infants.

During a normal pregnancy women should gain between twenty and thirty pounds. By continuing to eat proper foods that are good for you, you will not gain weight excessively. Proper foods do not include such foods as soft drinks, potato and corn chips, and pastries. These foods contain "empty" calories. They have little food value and take away from an appetite for proper foods that could be eaten. Eating proper foods does not demand beginning a strict diet immediately. Moderate changes in eating habits over a few weeks and months will help ease the change to better eating patterns. Except for certain cases, such as mothers with diabetes, there is little scientific justification for severe caloric or weight restriction. Infants of average or above average birthweight grow more and perform better throughout their first year than do low birthweight infants.

You can get help in planning a well-balanced diet during your pregnancy. The Women-Infants-Children (WIC) program of the Lake County Department of Public Health makes extra food available to pregnant and nursing women, babies and children under five years. WIC teaches how important good nutrition is for good health. You may be able to take part in the program or at least have professionals refer you to the proper nutrition information. Your obstetrician should also be able to give you the proper dietary information or lead you to someone who can. You could contact private nutritionists through the Lake County Health Department, your local hospital, or a Lamaze instructor.

Alcohol, Drugs and Medication

Over-the-counter drugs like aspirin, prescription drugs, alcohol consumption and cigarette smoking have all been linked with the incidence of developmental disabilities.

The simple rule for taking any kind of medicine during pregnancy is this: Do not take any medicine of any kind unless it has been prescribed or approved by your obstetrician. Make sure the doctor knows about all the medicine you are taking before obtaining any other prescriptions. Some medications, such as antihistamines, may be quite safe if taken on their own, but can be very dangerous when combined with other medicines or alcohol.

The placenta, the part of the mother's uterus through which the fetus is nourished, does not act as a barrier to harmful drugs and other substances. In fact, the unborn child often yields to drugs more easily than the mother. While the mother's body may be able to break down the effects of a certain drug within a few hours, the fetus' primitive defense system may take two or three days to rid itself of the same drug. If taken regularly, the fetus may be unable to rid itself of the drug and may suffer permanent damage.

Drinking more than three ounces of absolute alcohol per day (the equivalent of six average-sized drinks) has been proven to cause serious risk of handicap for the newborn child. It is not known, however at what level alcohol begins to harm the fetus. There is still much to learn about this problem, including the risks of moderate drinking and periodic heavy drinking. A useful guide is the "Two Drink Limit". Drink no more than one ounce of absolute alcohol each day. That equals two mixed drinks containing one ounce of liquor each, or two five-ounce glasses of wine, or two twelve-ounce cans of beer. If it is at all possible, avoid any consumption of alcohol during your pregnancy.

Infants of smoking mothers may have lower birthweight and damage to their blood vessels. The best advice is to quit smoking if you can. At a minimum cut down the number of cigarettes that you do smoke and switch to a brand with lower tar and nicotine content. Low birthweight children, as mentioned above, have a greater likelihood of developing handicaps than do average birthweight children.

Diseases

There are some diseases that can harm the unborn child, but have only a mild effect on the mother. Rubella, or German measles, is a mild childhood disease whose symptoms--slight fever, rash, sometimes swelling of the glands in the back of the neck--last about three days. The disease may be dangerous to a pregnant woman who did not have German measles when she was younger. There is never a safe time during a pregnancy to have rubella. The earlier in the pregnancy an expectant mother contracts rubella, the greater the danger to the child she is carrying. There is a vaccination which can be given to women of child bearing age to prevent them from getting the disease. It must be administered at least three months before conception to be effective.

If you are already pregnant and are not sure whether you have had German measles or are vaccinated against them, it would be wise to stay out of contact with groups of children if possible. The disease is common in children and by isolating yourself, you lower the risk of becoming infected.

Another infection, toxoplasmosis, can also affect the fetus. As with rubella, this organism may infect the pregnant woman without any symptoms. Domestic pets such as cats and birds may harbor the disease, so have them screened by your veterinarian. Luckily, toxoplasmosis is not transferred from person to person. As of now, no vaccination exists.

Avoiding these and other diseases by vaccination or testing for immunity before pregnancy is the best way to prevent the possibility of a handicapped child. If this is not possible, then avoid contact with large numbers of people who could be possible carriers of diseases. Immunity tests and vaccinations can be given by your family doctor.

Preparing for Childbirth

One of the most important things that you can do while pregnant is to see an obstetrician regularly. With regular check-ups and consultations, the obstetrician should be able to keep you on the right track to a healthy and safe pregnancy. The hospital in which you might have your child should have a special program to acquaint you with hospital procedures for delivery and also provide information for good nutrition and special exercises that may help with the delivery process.

The Lamaze method of childbirth is a program of exercises that are intended to ease the delivery process. Lamaze classes teach prospective mothers and their coaches (husband, relative, or friend) about the delivery process. Exercises and breathing techniques enable mothers to cooperate in the child's delivery as part of the medical team. Relaxed, confident mothers trained in the Lamaze method have healthier babies. Classes are offered to prospective parents during the last three months of the pregnancy. The Northern Illinois Chapter of Lamaze (American Society for Psychoprophylaxis in Obstetrics) in Highland Park can provide you with reading materials and names of teachers in your area.

Delivery

In preparation for the birth of the child, you can make sure that the hospital you choose engages in procedures that help ensure the child's good health. State law provides for a blood test for newborns that screens for a disease known as phenylketonuria (PKU). Early detection is important because if PKU is discovered early, the child can immediately be put on a restricted diet that may prevent the almost inevitable retardation that would otherwise occur. There are still some hospitals that do not comply with the law so check ahead.

The Illinois Association for Retarded Citizens has recently had a blood test for hypothyroidism mandated by state law. The test can be done from the same blood sample as the PKU test. Hypothyroidism is deficient thyroid hormone production resulting in mental retardation if not treated soon after birth. Although the number of babies affected by PKU and hypothyroidism is very small, the tests are not harmful to the child and can only be helpful. Make sure the hospital that you are going to does these tests.

The delivery process is sometimes long and painful. Often doctors recommend either a local or a general anesthetic depending on the amount of pain the mother experiences. Tests on newborn babies have found that those children whose mothers have received pain killing drugs took as long as three to seven days to completely recovery from the effects of the drug. For most children this does not cause any harm, but there is some degree of risk. If it is possible, mothers should avoid the use of pain killing drugs during labor and delivery unless an emergency arises.

If problems arise during labor and delivery and your baby has critical troubles (such as prematurity or birth defects), perinatal centers have special staffs and equipment to handle the situation. The three perinatal centers closest to Lake County are Rockford Memorial, Evanston and Lutheran General hospitals. The staffs of each perinatal center know which beds are open in which hospitals so your baby will be treated at the closest available hospital. Mothers who are identified as high risk can plan to deliver their babies at a perinatal center. Mothers who have children transferred to a perinatal center can request that they be transferred too.

Growing Up

Childhood illnesses can lead to serious disabilities. With immunizations, many formerly common diseases (polio, diphtheria, whooping cough, measles, mumps, and rubella) have nearly disappeared. But they are not gone completely. It is important that children be vaccinated against these diseases and get their follow-up or booster shots on schedule. At the beginning of each school year, the Lake County Public Health Department schedules appointments for immunizations which are needed for children's admittance to schools. Many of the services are free, so take advantage of them. There is some controversy about the safety of vaccinations so check with your family doctor to see where his or her preferences lie.

See the immunization schedule below for the appropriate ages for immunizations.

Routine Childhood Immunization Schedule

Disease	Immunization	Dates Given	Boosters
"Polio" (poliomyelitis)	Sabin vaccine: TOPV (trivalent oral poliovirus vaccine)	3 doses within the first 6 months of life, at roughly 1-2 month intervals (usually at 2, 4, and 6 months of age)	18 months, 4 years

Disease	Immunization	Dates Given	Boosters
Diphtheria tetanus/ pertussis (whooping cough)	DPT: diphtheria and tetanus toxoids combined with pertussis vaccine	Same as polio	Same as polio, but after 6 years of age booster given every 10 years of Td, combined tetanus and diphtheria toxoids (adult); first booster given at 14-16 years
Tetanus			For clean wounds no tetanus booster needed if child has had DPT or Td immunization within 10 years; for contaminated wounds, within five years.*
Measles/ mumps rubella (German measles)	M/M/R: combined (trivalent) vaccine of measles, mumps and rubella (or measles and rubella) can be given in place of single shots of each vaccine	Not before 1 year of age (unless serious epidemic)	No booster
Tuberculosis (TB)	Tuberculin test is not an immunization but an injection in the skin to test for the disease	Before (or at) time of DPT and if test measles positive	Annually if TB prevalent; annual x-ray vaccine remains
Smallpox**			

*Many doctors now prefer to use a gamma globulin preparation instead of booster in these cases.

**Immunization is not now given, since illness and death related to the vaccine is a greater threat than the risk of the disease, itself. Exceptions are made for those traveling to known smallpox areas of the world.

Accidents and poisonings cause more fatalities and crippling injuries than birth defects and disease. You cannot prevent every accident or injury to your child. Accidents are natural and part of the process of living. You can, however, make your home and neighborhoods safe for your child by following some of the advice given in pamphlets like Young Children and Accidents in the Home, put out by the Children's Bureau of the Department of Health, Education, and Welfare. Since they only have limited supplies, this specific pamphlet may not be available. You should ask for any materials on accidents and poisonings in general.

In Summary

If you are considering having another child, there are many things that you can do to ensure that the child will have the best chances possible to grow up healthy. There are agencies in Lake County (for example, Lake County Public Health Department, the Health Systems Agency of Kane, Lake, and McHenry Counties, the special education districts) that are working on the prevention of developmental disabilities. They can help you by providing the latest information on medical and nutritional developments as the information in this section becomes outdated. As parents, you are the most influential people in your child's life. Use the information and services that are available to ensure the best possibilities for a healthy life for your children.

Recommended for Further Reading

Brazelton, T. Berry. Infants and Mothers: Differences in Development.
1969 New York: Delta.
Month by month descriptions of the behavior of children in the first year of life. Differences in the achievement of growth are highlighted by the presentation of contrasts between the quiet, average, and active baby.

Milunsky, Aubrey, M.D. Know Your Genes. Boston: Houghton-Mifflin.
1977 Written in non-technical terms, the author describes genetic counseling and recently developed techniques of prenatal diagnosis and carrier detection, their safety, accuracy and who needs them. Diseases, birth defects, and drug reactions resulting from the interaction of genes and environment are fully discussed.

McNamara, Joan and Bernard. The Special Child Handbook. New York: Hawthorn
1977 Books.
A non-technical manual for parents of children who have special needs, based on personal and professional experience of the authors. This manual expands on every subject we have covered in our manual, giving more examples and information than we had room for. A very good book to have for your reference throughout your child's lifetime.

Spock, Benjamin. Baby and Child Care. New York: Pocket Books.
1976 Best-selling handbook for parents ever published with over 28 million copies sold. It is a very practical guide, especially to childhood disease and illness. There have been several editions published since 1946, so make sure to get the most current one.

For pamphlets on preventing accidents and poisoning write to:

Children's Bureau of Child Development
Office of Human Development
Department of Health, Education, and Welfare
Washington, D.C. 20201

ask for: Young Children and Accidents in the Home, DHEW publication No. (OHD) 76-30034

For pamphlets on immunization write to:

Center for Disease Control
Public Health Service
U.S. Dept. of Health, Education, and Welfare
Washington, D.C. 20201

ask for: Parents' Guide to Childhood Immunization October 1977, DHEW Pub. No. (OS) 77-50058

If you're interested in amniocentesis and genetic counseling but cannot arrange a referral through your own doctor, there are two national organizations that will refer you to an appropriate medical center in your vicinity:

The National Foundation-March of Dimes makes referrals from its Internanational Directory of Genetic Service, a listing of medical centers throughout the world. If your local March of Dimes chapter doesn't have a copy, send a stamped, self-addressed envelope to: Science Information Division, National Foundation-March of Dimes, Box 2000, White Plains, N.Y. 10602. Ask for the listings that apply to your area.

The National Genetics Foundation makes referrals to medical centers throughout the country. "We're very selective," says Ruth Berini, the executive director. "The only centers we refer patients to are those with very stable lab results." The foundation also supplies literature on amniocentesis, genetic disease, and genetic counseling, as well as a "Family Health History: questionnaire to fill out. For information, write to: National Genetics Foundation Inc., 9 West 57th Street, NYC 10019.

CONSUMER ACTION

Parents are the most important part of the team of specialists who work with developmentally disabled children. They are the only members of the team who remain with the child throughout the life cycle. Parents' observations at home provide an important check on programs' reports about children's abilities. Starting with the baby book, it is important that parents keep detailed accurate records to ensure proper diagnosis, assessment, and placement. Comprehensive records maximize the benefits to be gained when any new facility or service is contacted. Parents are considered as consumers in terms of: the needs of their children, their children's programs, their membership in parents' organizations, the planning of programs, and legal and legislative advocacy.

As a beginning, parents can improve their children's home environments. For some families relatively minor adjustments are necessary in the home or in family interactions. For others, however, the requirements of a developmentally disabled child in the home could seem overwhelming. The impact of the child's disability on family routines can be minimized by changing such things as home design, clothing, equipment, or seemingly simple things such as toys, play, going to the supermarket or eating meals. The Chapter on Needs of Children at Home provides educational activities and practical ideas that parents can use at home with their handicapped child.

Secondly, parents can have a say in how their children are educated and treated in programs in which they are enrolled. The Chapter on Children in Programs discusses selection and monitoring. Involvement with their children's educational and residential programs gives parents the opportunity to provide improvement in their children's developmental programming. While children are in school, by law parents must receive notice in writing before the school changes a child's program. Parents have the right to give -- or withhold -- permission for their child to be tested, evaluated, or placed; to see all school records; and to request a hearing if they disagree with any of the school's procedures. It is important that parents attend all meetings held to plan, evaluate, and change their child's educational program. Parents bring to bear broader concerns for the child's development. As a member of the team -- receiving and giving information, asking for and providing explanations -- children's school progress will be smoother and have continuity. Professionals can then become valued consultants if a child's behavior or abilities change, if discipline becomes a problem, for example, or if it seems a different educational program might be better for a child.

Thirdly, parents can participate in existing organizations. At first parents are usually preoccupied with their own children. Later, many come to the realization the programs will die or be cut back if they do not fight for the rights and dignity of all developmentally disabled persons in their community, state, and whole nation. Parents' organizations have developed through sharing common concerns, setting up their own facilities, to becoming thoroughgoing advocates. Parents can become involved in parents' organizations in many ways -- in the administration of programs, by starting new programs, and advocating for the legal rights of their child and handicapped persons in general. The Chapter on Parents' Organizations covers responsibilities of membership and the types of organizations available.

Fourthly, parents can plan new programs. Although a great deal of progress has been made in the provision of services over the last three decades, there are still unmet needs. The Chapter on Parents as Planners outlines the components of a comprehensive network of services to facilitate the identification of service gaps. Filling service gaps can be accomplished either through existing organizations or by starting new ones. Beginning suggestions for both alternatives are provided.

Finally, parents can become advocates for their own and all developmentally disabled persons. The Chapter on Legal and Legislative Advocates outlines specific legal rights of developmentally disabled children not only in education, but also in health, employment, voting, driving, public transportation, residential facilities, and economic welfare. There are a number of private and government programs designed to promote appropriate educational, employment, and living environments. Only through continuous monitoring of available services and programs can parents ensure that legal requirements are met; only through constant advocacy at the community, state, and federal level will new legislation be enacted to upgrade current legal requirements.

Parents And The Needs Of Children At Home

This section is designed to assist you with the special needs of your developmentally disabled child at home. For some families relatively minor adjustments are necessary; for others, more major changes may be worth the effort. This chapter offers suggestions about everyday activities at home, clothing, and home design.

While children with developmental disabilities need special considerations, they are primarily children. All children need supportive homes, where they can have the freedom to choose among appropriate options, with responsible adults helping to define limits to that freedom. The degree of your child's developmental disability will define the amounts and kinds of repetition, expectations and rewards which are appropriate. The experience of learning and teaching, and the commitment and investment in that child are the same as for any child. The rewards and satisfactions may even be greater and more exciting because of your extra effort.

Developmental Activities at Home

All children develop at their own rates. Some will have spurts; some will develop very gradually; some will develop well in one area but lag in another; some will develop quickly and then later slow down. There are averages for the attainment of developmental milestones. For developmentally disabled children these milestones can be used as guidelines for sequencing tasks to be attempted. One of the most difficult challenges for any parent is to permit your child to develop at his/her own pace. Avoid the temptation to make comparisons with developmental guidelines for "average" children. Your child's abilities can be discovered by noticing progress. By close observations of your child you will be able to tell when to encourage further development, at what speed your child can learn, and where your child seems to do best. If your child is less than three years old, an Early Intervention Program will offer more specific help. For older children, school personnel can offer valuable suggestions to complement classroom activities and therapy.

Language

Starting with the first smile, there are various stages that a baby must go through before beginning to talk. These include cooing, gurgling, laughing, squealing, and babbling. Each of these skills must be mastered before the next one can be learned.

Babies make all kinds of noises, which develop into sounds that resemble parts of words: "ba", "da", "ma", "goo", "ta". These are called babbling sounds. Listen for these sounds. You want your child to work on these sounds, because they are the ones he or she will be putting together into words. Play with these sounds, showing your child how to make them. Whenever your child makes a babbling sound, do not let it slip away without responding. Repeat the sound using a lot of facial expression. Repeat it again changing the tone of your voice, making your voice go high or low. Try to get your child to imitate sounds you have already heard him or her make. Once you succeed in getting your child to imitate a sound you have made, you can begin to change those sounds, and teach your child new ones. Children learn to speak best when you talk directly to them.

Start slowly, and only move on when you see progress. Patience and simplicity are the key words in helping your child learn to communicate. Be persistent. Incorporate your exercises into daily play.

Keep in mind that a child's attention span is brief. Try and keep your responses short and precise, as your child may forget quickly if a long explanation or question is given. Repeat the same short phrases several times, with slightly different variations. Repetition is a good way to learn and can become an enjoyable game.

The grocery store can be a great place for practicing communication by identifying differences and similarities in foods. It seems to be most effective if only one or two ideas are involved. When taking cans off a shelf describe the colors; ask your child to point to a certain color or a certain food and to repeat the word. Then, ask your child to find the same color or shape or food somewhere else, and so on. These same learning games can become part of mealtimes and other shared family activities. As your child's abilities develop, these games with language can become more complex.

Movement

Stages of development of movement and coordination may be delayed but you cannot let valuable time slip away. Start stimulating movement as soon as possible with your child. If your child does not lift his or her head up, after the fourth month pick up your child holding the head firmly so that objects around can be seen. Show your child colorful objects and get your child's eyes to follow them as you move the objects. Place objects into your child's hands. Some children will not be able to sit alone without support until well into their second year of life. This developmental step can be encouraged by propping up the baby against pillows (at about 10 months) or by using baby chairs.

All muscles in the child's body need to be exercised. Raise the feet and legs to encourage leg movements. Pull the baby carefully into a sitting position (after 4 months) to encourage development of the back and neck muscles. When your child can sit, introduce kneeling, by gently placing him or her in that position. Give your child support with your arms to encourage standing. When your child can stand with support, encourage walking by holding onto his or her hands and gently pulling forward.

Always encourage your child to do as much as possible and to work towards improvement, even if movements are awkward. For example, mealtimes are extremely important as a family time. If the child is just beginning to learn to eat, the resulting mess and amount of help required may be disruptive for the rest of the family members. One idea to make learning to eat a more pleasant experience is to allow your child to eat the main meal before the rest of the family, then to give your child "finger-foods" (such as cheerios, crackers, carrots, and bananas) at the table while the rest of the family eats. This way your child is a part of the family, is not as disruptive of others' meals, and fine motor coordination is being encouraged.

Limit the number of skills being taught at any one time. For example, until the child has mastered using a spoon, try to disregard the mess on the floor and on the child. (An old shower curtain can be used as a drop cloth under the child's chair and is easily wiped off.) Once the first step, the spoon, has been handled, the concept of the napkin might then be introduced. For older children, an example might be to get them to help with meal preparation by having them put nonbreakable items on the table. Again, motor coordination is being encouraged, and your child is receiving extra attention and affection while learning to become as self-sufficient as possible.

Self-help Skills

What exactly is meant by "self-help skills"? Self-help skills are the most basic skills that children learn in order to care for themselves. These include feeding, toilet training, dressing, cleanliness, grooming, and caring for one's own property. These skills, usually taken for granted, often must be painstakingly learned step by step by developmentally disabled children.

Babies begin to acquire self-help skills from their first day. For example, for most children sucking is a natural reflex that does not have to be learned. Some children, however, must be taught to suck. When babies begin to bottle feed, some grasp the bottle firmly, whereas others need to be taught how to hold onto it. Bottle and spoon feeding will most probably be used for a longer time than with the average child but the developmental sequence of learning skills will be the same.

Show your child how to get dressed and undressed by guiding the child's hands through the motions. At first, you might just leave the last step for the child, for example, let a sock hang from the very last toe and let the child pull the sock off. Shirts that do not have buttons on them are much easier to use than those that do. Be careful not to "take over" too often. Try small steps so you can allow yourself enough time to be patient while your child attempts that step.

After your child learns to walk, and can carry objects, you can start teaching him or her how to set the table, and how to help you with other chores around the house. Find some activity that the child is capable of learning, and make that activity a useful and vital part of your household routine.

The average child responds to toilet training anywhere between the ages of 16 months and 3 years. Developmentally disabled children in general will be older, depending upon the severity of the disability. Before you can teach self-initiated toileting your child must be able to walk to the toilet, be able to pull his or her pants up and down, and have an understanding of simple commands. Foxx and Azrin have published a manual for program staff called Toilet Training the Retarded which you could use as a guideline as well. Talk to your child's teachers, and try to observe in the classroom, to make sure the same commands and procedures are being used at home and at school.

Frustration, Discipline, and Limit-Setting

If your child is not ready for a new task or activity, try again at a later date. Do not push your child beyond his or her capabilities. Discouragement from continued failure blocks learning. On the other hand, children can learn to pretend ignorance in order to get you to continue to cater to them. Listen to what teachers and therapists tell you your child is doing at school; tell them what your child is doing at home. Make sure valuable time is not being lost, at home or at school, either because too much or too little is being expected. Step by step, with the days, months, and years of encouragement, you will see your child developing new skills. Throughout these activities remember the importance of communication. Use speech and gestures at all times.

Throughout all of these experiences and learning patterns, both you and your child at some point may begin to feel frustrated by the seeming lack of progress. That's just "normal operating procedure" and, in fact, it can be healthy to acknowledge this feeling. The admission of frustration can often lead to modifications and further trials. As for the child's feelings of frustration, this too can be healthy. A child needs to learn to cope with such normal feelings. The attempt to remove all barriers to learning and development, in fact, may prove to be somewhat detrimental. Let your child's developmental stage (not your child's age in years) set your expectations for your child.

An area of frequent concern for parents is discipline or limit-setting. The methods and kinds of parental discipline should be the same as for any child. Explanations and restraint work best in teaching your child self-discipline. All children need to be aware of socially acceptable behavior. It may not seem so necessary when your child is young but as adolescents, inappropriate behavior will not be as readily tolerated by others. Skills like learning to get dressed, and how to dress properly for different situations and for different kinds of weather, have an effect on how others will relate to your child.

Modifying Your Home Environment

There are many ways in which your daily life patterns can be modified to incorporate learning experiences for your child. For instance, if you have a pet at home, your child's experience with that pet can help in developing relationships with people.

Toys and Books

Books and toys (whether purchased or created from items in the home) are crucial for any child's development. Check with your child's pediatrician, teacher or therapist about which kinds of skills your child needs most to practice so you can purchase or make toys and books accordingly. Many toy manufacturers will send you a list of their toys which may be especially suited to your child. Ask teachers and therapists for catalogues of educational toys and books. School and community librarians are obvious resources.

Clothing

Dressing can be a real challenge because of the way clothes are made. Zippers may be unreachable, buttons may be too small, belts may make it difficult to lower pants for going to the bathroom, raising or turning the arms to put on a dress or shirt may seem an impossibility. Three main criteria to keep in mind are that your child's clothing should be comfortable, look attractive, and allow independence in dressing and undressing. Two examples of modifications possible are to replace zippers or buttons with velcro fasteners, and to buy shoes without laces. Veterans' hospitals and rehabilitation centers may have staff available for consultation on more complex problems.

Home Design

A more time consuming and difficult task is that of restyling your home to allow your child freedom of movement. In some cases, only minor interior adjustments are needed such as lowering the telephone, or raising the electrical outlets. A light switch on the outside of a room makes entering much simpler. In the bathroom, grab bars in the bath tub are fairly easy to install. If the bathroom is small, grab bars on the inside and the outside of the door frame can help in moving from a wheel chair to a standing position. Flexible shower attachments make bathing more comfortable and safer. Guard-rails, elevated seats, and wall-mounts can be built to make using the toilet easier.

In the kitchen if remodeling can be done keep in mind such things as:

-accessibility (how close cabinets are to refrigerator and stove, since a kitchen which is long and spacious may actually be inefficient for the disabled person);

-level (while sitting on a chair or stool or wheelchair, the handicapped person should be able to reach the counters comfortably);

-continuity of counter space (nothing between refrigerator, sink and stove so that a disabled person does not have to carry or lift kitchen items);

If remodeling is a problem, and it can be expensive, some simple ideas are:

-using Lazy Susans and pegboards for storing pots and pans at the right height;

-utilizing free standing cabinets with casters for easier mobility;

-making stoves safer or more convenient by having the controls on the top, in the front, or on the side;

-buying a refrigerator with the freezer on the bottom for easier access.

These are only brief descriptions of some modifications that can make life a little easier for your child. We hope these suggestions will stimulate your own creativity and further reading.

Recommended for Further Reading

Boyd, Neva L. 1975 Handbook of Recreational Games. New York: Dover. Originally published in 1945, this book contains the rules for many common games that children play. Includes rules and diagrams for 18 categories of games with up to 59 games in a category. Examples are hopping and jumping games, throwing and catching games, bouncing ball games, and vocabulary games.

Boyd, Neva L. 1945 Hospital and Bedside Games. Chicago, Illinois: H. T. FitzSimons. A collection of games originally compiled in response to requests for activities at which people in hospitals could play. Many of the games are too advanced for young children, but some are applicable.

Caplan, Frank. The First Twelve Months of Life. New York: Bantam.
1971 The book describes the sequencing of normal and expected infant behaviors and infant rearing practices. The discussion of a child's growth month by month with accompanying charts for motor, language, mental and social development will help you understand and assist your child through the stages of development regardless of rate of progress.

Cary, Jane Randolph. How to Create Interiors for the Disabled. New York:
1978 Pantheon Books.
A guidebook for families and friends of the disabled for the construction of home environments that are useful and comfortable for the disabled.

Foxx, Richard M. and Nathan H. Azrin. Toilet Training the Retarded: A
1973 Rapid Program for Day and Nighttime Independent Toileting. Champaign, Illinois: Research Press.
Detailed step-by-step descriptions of techniques used in toilet training the retarded. Written for special educators, residential program staff, and parents. Contains examples of charts for keeping track of the child's progress, and information on special equipment and clothing.

Hartley, Ruth E. and Robert M. Goldenson. The Complete Book of Children's
1963 Play. New York: Thomas Y. Crowell.
Information on children's play from birth to adolescence, designed to use the special characteristics of each year's growth to plan rewarding play experiences. Contains practical lists of materials and resources including household items to save and use in play.

Ilg, Frances and Louise Bates Ames. The Gesell Institute's Child Behavior
1955 from Birth to Ten. New York: Harper & Row.
Practical guide for parents. Discusses children's behaviors within the context of their growth and development. If you focus on your child's developmental stage (rather than the chronological ages given as guidelines) this book can help you with the timing of information given to your child.

Junior League of Spartanburg. The Cooking Kit. The Junior League of Spar-
1977 tanburg, Inc., P.O. Box 2881, Spartanburg, South Carolina 29304.
Cookbook written on a second grade and under reading level as an aid to cooking, selection of recipes, and meal planning. Every step in the preparation of a recipe is illustrated and color-coded. A set of aluminum measuring cups and spoons, color-coded to the measurements in the recipes, is packed with each cookbook.

Klinger, Judith Lannefeld. Mealtime Manual for People with Disabilities
1978 and the Aging. Campbell Soup Company, Box (MM)56, Camden, New Jersey 08101.
Primarily designed for the physically handicapped homemaker. Useful for providing ideas about how to modify kitchens and utensils for the person in a wheelchair or who has problems working with both hands.

Lazar, Flora E. and Richard B. Lazar. A Resource Guide for the Physically
1978 Handicapped of Chicago. Access Chicago, Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, Illinois 60611.
Designed to help the physically handicapped gain access to community resources -- such as, transportation, employment, housing, recreation, and education — as a part of independent living. Also contains a section on special equipment such as prosthetic-orthotic devices, telephones, and typewriters.

Lorton, Mary Baratta. Workjobs. Menlo Park, California: Addison-Wesley.
1972 Suggested activities for children which are designed to develop their skills in perception, matching, classification, number sequences, relationships, and others. An index at the end of the book lists the activities according to the skills which they develop.

Marzollo, Jean and Janice Lloyd. Learning Through Play. New York: Harper
1974 Colophon.
Written primarily for parents of children at the preschool developmental stage. Activities for developing children's skills with regard to the five senses, language, relationships, classifying, counting, measuring, problem solving, creativity, self-esteem, and others are included.

White, Burton L. The First Three Years of Life. Englewood Cliffs, New
1975 Jersey: Prentice-Hall.
Detailed guide to the intellectual and emotional development of the very young child. White divides the first three years into seven successive developmental phases for which he provides both a comprehensive description of the characteristic physical, emotional, and mental developments of which parents must be aware and a detailed list of instructions concerning childrearing practices, parental strategies, and even toys and equipment.

The Access Chicago book (see Lazar) was used as a model for a similar guidebook to North Suburban Chicago published by the League of Women Voters. Access North Suburban Chicago covers the geographical area from Waukegan and Gurnee to Des Plaines and Evanston. Included are stores, shopping centers, restaurants, theatres, places of worship, and office buildings. Copies can be obtained from: League of Women Voters of the Deerfield Area, P. O. Box 124, Deerfield, Illinois 60015.

Parents of Children in Programs

Becoming informed and being persistent are the two most important assets you can develop to ensure continuity between what you do at home with your child and the services your child receives at school, park district programs, or in therapy. To help your child effectively you must become involved in your child's programs.

The first step you must take whenever you want to have a say about a program is to find out about it. Perhaps the biggest problem is to find out the information you need. Remember that no question is too stupid to ask.

Selecting Programs

Selecting the program best suited for your child's abilities involves visiting the program(s) that is(are) available. Talk to teachers and administrators about the instruction and treatment your child would receive. Here are some of the kinds of questions to ask: If your child requires specific kinds of treatment, are they available? Do teachers have aides to help provide individual attention? Are special exercise and instructional facilities that your child needs available? How much do handicapped and non-handicapped children mix with one another? How can parents get involved in the program?

Visit the classrooms and other facilities that your child would be using to observe them in action. Try to picture your child in the program.

Once you have the information you need, act on it. Think of what needs to be done and plan a series of smaller steps to enroll your child in the program. Work on only one step at a time.

If you are seeking information about a private school, day school or residential facility, you may be guided by a list of 101 questions prepared by the American Association on Mental Deficiency. Order the list free from the Chicago office of the Illinois Association for Retarded Citizens. To help you evaluate public or private day schools, the Coordinating Council for Handicapped Children in Chicago has published a one-page checklist you can order for free. (See directory at back for addresses and telephone numbers.)

To find day care, you may run into problems. Lake County does not have enough licensed day care facilities to handle the demand for day care services, especially in Waukegan and North Chicago. If you want day care services (or if you want a license to offer them yourself), contact the Illinois Department of Children and Family Services, 4 South Genesee Street, Waukegan 60085, phone (312)244-4640.

To find out about certain kinds of services, you may even consult the yellow pages of the phone book. Some listings you may need are:

Day Nurseries
Employment Service-Government
Governmental Offices
Hospitals
Lawyers
Libraries
Marriage and Family Counselors
Medical Groups
Optometrists
Physicians and Surgeons' Information Bureau
Physicians
Podiatrists
Political Organizations
Psychologists
Railroads
Recreation Centers
Schools
Social Service Organizations
Telephone Companies
Translators and Interpreters

If you find an appropriate program but cannot get your child into it, get a clear explanation of the reasons your child was denied entry into the program you seek. Find out what criteria were used and who decided not to admit your child. You will need to know this information if you want to try to get the decision changed.

If you feel your child does have needs which require a particular program, consider obtaining an independent evaluation. You probably will have to pay for it yourself, but the program may be required to reimburse you if a state official later rules at a hearing that the program's evaluations were inappropriate. Have your own evaluation conducted by people who are qualified and certified by the state. Show those people your file of records of previous medical and educational evaluations, including copies of each test used to evaluate your child's needs by your local school. Ask that you receive copies of the independent evaluation when it is finished.

Finally, contact the program and tell it about the results of your independent evaluation. Insist in writing that the program's evaluation team consider the results. Request the evaluation team meet with the professionals who performed your independent evaluation, because listening to those professionals is the best way for program staff to learn about the independent evaluation.

It is unlikely you will have to take all these steps to get the program you want for your child. Most program staff usually respond well to special needs. But make sure program personnel do not leave you confused. They should be able to explain decisions to you simply and clearly. Make sure different staff members and professionals communicate with each other, too, so that you do not get stuck with a runaround whenever someone does not have the answer to your problem or question.

Monitoring Your Child's Educational Program

If you question or challenge actions or decisions made by a school in which your child is already placed, you will want to settle your differences of opinion as constructively as possible. If you are upset, do not get involved in angry personal confrontations, but convert your concern to action. Make sure you become familiar with your child's rights before you take action. Here are ten steps suggested by Common Sense from Closer Look, the publication of the Parents Campaign for Handicapped Children and Youth (Box 1492, Washington, D.C. 20013):

1. Talk to your child's classroom teacher and to other school people who are aware of your child's needs, such as the counselor, nurse, school psychologist or social worker. See if adjustments or changes can be made through understanding and cooperation.

2. If this does not work, find out who among these people is sympathetic to your needs. Ask them if they will be willing to come to meetings with you later, or to supply letters or statements supporting your position.

3. Discuss your concerns with outsiders, such as your family doctor, a parent advocate, or other parents in your school's parents' group.

4. Keep records of everything. Record dates and names for future reference.

5. Bring your concerns to the attention of the school principal. Present any documentation you have to him. Be self-assured, but not belligerent or apologetic. Stick to your argument. After this and other conferences, write a letter to the principal summarizing your understanding of your conversation.

6. If meeting the principal does not work for you, go to the Superintendent of your Special Education District if you live in areas served by SEDOL or NSSED, or to the Director of Special Education if you live in Waukegan. Again, present any documentation you have, and follow up the meeting with a letter.

When you meet with the principal or superintendent, ask to include in the discussion other people familiar with your child's problem.

7. If you still do not succeed, remember -- be persistent and assertive. Bring your complaint before the local school board. A sympathetic school board can bring about immediate action.

8. Also, get in touch with the Illinois Office of Education (see directory in the back of this handbook). Explain the problem in a letter, and ask what help the state can provide.

9. Illinois has complaint officers whose responsibility it is to investigate complaints and monitor the compliance of school systems with the law. Ask the Illinois Office of Education how you may get in touch with a complaint officer for information and advice.

10. Get others to help you. See if other members of your school's parents' group will help you by attending meetings or by writing letters in support of your cause. Contact an advocate; Illinois has a field advocate in Woodstock, and private advocates are available for a fee. As a final step, you can call for a due process hearing. For more information about this procedure, see the Chapter on "Parents as Legal and Legislative Advocates" in this handbook.

School and other officials may not consider you to be objective about your child's needs. They know you have a special interest in your child, and may try to discount your requests or put you off without giving you the answer you want. If this happens outside help is especially important to you.

If you are unsure about your child's rights or you are reluctant to challenge school administrators or teachers, the Coordinating Council for Handicapped Children in Chicago may help you. The Council operates frequent sessions in rights training. The training is designed to help you deal with school and other officials.

Parents as Members of Parents' Organizations

When Laremont School opened in Gages Lake in 1975, spectators watched games in Laremont's gym without a convenient record of the scores. But in 1978, Laremont's Parent-Teacher Federation held a springtime "fun fair" to raise money for the school. As a result, Laremont installed its first scoreboard.

This is only one example of many achievements of parents of developmentally disabled children in Lake County. No one parent had enough money to purchase a scoreboard. Together, however, the parents provided a way to purchase one.

Together, parents can influence the content of education programs and set priorities for the future. They can alert the public to special needs of their children. They can lobby for new laws at the local, state and national levels. They can bring pressure on local schools and agencies to better serve the developmentally disabled. They can sponsor social events and provide basic services to one another such as babysitting and tutoring.

Parents can accomplish many things when they organize. Parent groups are the single most important factor behind the progress made in recent years in the rights of handicapped children. Today, parent groups continue to break new ground.

A parent group brings together people with common interests. A group will help you find that your problems as the parent of a handicapped child are shared by others.

Becoming a Member

If you are the kind of person who has been involved in clubs and organizations all your life then you will probably find it quite easy and an enjoyable new experience to join another group. If you have not become skilled at joining groups, then it will take longer to make friends and to feel accepted. Everyone feels awkward and like an outsider when they first attend a meeting of an on-going group. Experienced people have just learned to persist until those feelings are replaced by a feeling of belongingness. Plan to attend enough meetings to give the group a chance. Volunteer for small tasks at first -- helping with refreshments, for example. Look for people who seem to be alone and ask them about their children. If your child has developed friendships at school, ask the teacher to introduce you to the parents of those children. Do not be afraid to join a group of people who are talking and just quietly listen. Even if you do not understand everything they are talking about right then, whatever you learn will help you to understand and be more involved later. Professionals new to the field of developmental disabilities say it takes about six months to learn all the new terminology ("labels" or "jargon")--and they are involved in talking to informed others 40 hours a week or so!

Pace yourself. Only attempt what you can realistically undertake at the time. Try to keep your involvement at a level which you can maintain over the long haul. Do not undertake so much that you will "burn out" or so little that you always feel like an outsider. There will be times when you can put a lot of effort into a short-range project, such as working for a bazaar or a particularly important piece of legislation. There will be other times when attending meetings is the extent of the commitment you can manage. Say "yes" to requests when you have the time, can make a contribution, and can learn from a new experience. Say "no" and give an explanation or offer an alternative when you feel too much is being asked of you at a particular time. It is important to develop a reputation for following through on commitments, however small or large, to remain valued as a group member. Do not let yourself and others down by making unrealistic offers.

Keep in mind, too, that other people often lack skills in being effective group members. Sometimes you will have to listen while someone dominates a meeting with their own narrow concerns. Sometimes others will be rude and unpleasant. If you have a history of pleasant and rewarding experiences with a group, then an unpleasant encounter will not bother you too much. But if it is one of your first meetings, you may feel so badly that you do not want to return. Again, give the group a chance by going to enough meetings so that you can determine whether what happened was an unusual event or whether the group really is not right for you. In the latter case, try a different group or speak to some other parents to see if they share your feelings and will work with you to remedy the problem.

Above all, choose a group that utilizes your energy and helps you develop your talents, while accomplishing a desired goal for your child as well. You do not have to attend every meeting of an organization to accomplish these goals for yourself and your child. You do have to attend often enough to maintain continuity with the group. If transportation or babysitters are a problem, cooperative arrangements to take turns with other parents can often be worked out. Speak to the group's officers if you do not know how to set up such arrangements on your own.

Types of Parents' Organizations

Parents' organizations can be divided into three general types that sometimes overlap:

1. Groups of parents whose children are in specific programs. These groups are common throughout Lake County. Many public schools, special education schools and residential facilities have organizations of parents which help support programs. Parent Teacher Federations are an example.

2. Local special interest or service groups. These may include not only parents of developmentally disabled children, but other interested citizens as well. These groups are not tied to a specific school or other institution. The Down's Developmental Counsel and United Cerebral Palsy of Greater Chicago, both described later, are examples of such organizations.

3. State and national organizations. These usually rely on individual paid memberships to support professional staffs working toward specific goals. Some examples described later include the Illinois Epilepsy Association and the National Association for Retarded Citizens.

In addition to attending meetings of any of these types of organizations, parents can also take advantage of many volunteer opportunities in institutions and communities where parents' organizations do not exist. If you see an unmet need, you may want to join with other parents to set up a new organization.

Here is a description of some groups. Keep in mind that this is not a comprehensive list, and that specific information may change. If you are already part of a parent group, this list may give you new ideas for your group. It also provides a starting point of places and people to contact.

Groups at Specific Facilities

Laremont School, the Special Education District of Lake County's (SEDOL) school for moderately handicapped children has a Parent Teacher Federation (PTF). The PTF meets quarterly and publishes a quarterly newsletter, The Lion's Roar. The group provides support to the school in social and recreational activities, and fund raising. PTF publicizes school activities in the local newspapers. Parents in PTF are encouraged to join the Illinois Association for Retarded Citizens. Students at Laremont bring home notices of upcoming meetings.

The Sally Potter School, part of SEDOL, has a new Parent Teacher Association. The school's students are physically handicapped. The association plans to assist school recreation programs, raise money, disseminate information, encourage research, and enhance the relationship between school and home life. The membership meets four times a year.

SEDOL's Hearing Impaired Program for children who are deaf or hard of hearing, has a Parent Teacher Organization (PTO). The PTO meets every other month. It sponsors social events, sponsors programs for parents and the public (including a sign language class), and publishes a newsletter.

Stratford School, part of the Northern Suburban Special Education District (NSSED), has a Parent Teacher Organization (PTO). The PTO has monthly meetings and publishes a newsletter. Its goals and functions are similar to those described for Laremont School. Its members recently constructed a greenhouse at the school. PTO members have the option of joining the Illinois Association for Retarded Citizens.

NSSED has a school system-wide parent group called CHILD -- Concerned Help in Learning Development. CHILD meets three times a year, and its meetings feature speakers on subjects of interest to parents. CHILD members also provide referrals and mutual support.

The Waukegan Community Unit District No. 60 has a Parent Advisory Council (PAC) made up of all parents of children in special education programs throughout the district. PAC supplements the typical parent teacher associations at individual schools. Like the parent groups at Stratford and Laremont, the PAC is designed to build support for the schools and to educate parents. PAC plans meetings with speakers, social events and other activities. Teachers and school administrators are advisory members of the group.

The Lambs Inc., a residential and employment facility for adults with developmental disabilities, has a parents' organization. Membership is required for parents of the workers.

The Head Start Center Committee. Parents at each of Lake County's seven Head Start centers for pre-school children are members of this committee.

If your child's school or facility is not included above, telephone the school and ask if it has a parent group. If it does, get the name and phone number of an officer in the group for further information.

Not all schools and facilities have parent groups. The Grove School, in Lake Forest, which trains severely and profoundly handicapped children and young adults, has no parent group, but does offer many opportunities for volunteer work. You can take part in the day school, swimming program, arts and crafts program, field trips and many other activities. The Countryside Center for the Handicapped in Barrington and the Riverside Foundation in Mundelein are other examples of places without parents' groups that welcome volunteer help. Whether or not your child's school or facility has a parent group, ask how you can help as a volunteer.

Local Groups

Some local groups are independent organizations. Others are chapters of state or national organizations. Both types are represented below.

The Coordinating Council for Handicapped Children serves Chicago primarily, but also Lake County and other outlying areas. The CCHC publishes a newsletter, offers free training sessions for parents and professionals, publishes books, and advocates for the handicapped.

The Downs' Development Counsel matches parents of older children with Down's Syndrome with parents of new borns with Down's Syndrome to help the new parents cope. The Counsel has published information about its functions.

The Easter Seals Society for Crippled Children and Adults is a national organization set up to provide direct services such as therapy to handicapped people and their families. It also engages in educational programs.

In Lake County, the society has an active chapter that offers speech and physical therapy for both the mentally and physically handicapped. The society loans equipment for home use, and it offers information and referral to other agencies if necessary. The society also works to eliminate architectural barriers for the physically handicapped.

The Epilepsy Foundation of America has a North Shore-Lake County chapter. The chapter has a consumer council and a self-help group that meets monthly. The chapter's offices handle legal advocacy, referrals, and management of specific cases. EFA members receive a discount on medication.

The Learning Exchange is a link. It connects people interested in teaching, learning, or sharing an interest. People can get together in groups or in one-to-one meetings whenever you and the others you will meet with agree to meet. The exchange serves the entire Chicago area, including Lake County. More than 15,000 people have participated in exchanges on more than 2,000 subjects. Members get a catalog, a quarterly newsletter, a membership card and access to a "members only" telephone directory.

The National Society for Autistic Children has a Greater Chicago chapter which serves Lake County. An attempt was once made to set up a chapter for Lake County alone, but its founders said too few autistic people live in the county to make such a chapter viable. The Greater Chicago chapter disseminates information about autism, operates a referral service, solicits funds, invites experts to its meetings, and advocates for autistic people.

United Cerebral Palsy of Greater Chicago has a North Side adult club open to Lake County members. The UCP provides programs in leisure and self-expression. It provides a day camp in Gurnee and educational and therapy facilities for children. UCP also has social workers who visit homes and provide counseling.

The Women's Board of The Lambs, Inc. is a community group that supports programs of The Lambs in Libertyville. Among other things, the board holds an annual Harvest Ball in October to raise money.

State and National Organizations

State and national organizations of the same disability group may offer different opportunities and information. Check to see what each has to offer.

Advocates for the Handicapped is a statewide organization seeking to promote the common needs of the handicapped, assure maximum opportunities for them, advocate for their rights and sponsor educational programs.

The Down's Syndrome Congress is a national organization seeking to promote the welfare of persons with Down's Syndrome. The organization publishes a newsletter.

The Illinois Alliance for Exceptional Children and Adults is a coalition of smaller organizations whose members include parents and professionals. The group seeks to encourage public awareness of the rights, needs and capabilities of exceptional people.

The Illinois Association for Retarded Citizens, the state arm of the national ARC, links local ARC units together and promotes the rights of retarded citizens on the state level. The National Association for Retarded Citizens promotes the welfare of mentally retarded people. It works for improved care, treatment, training, education, public education and integration of community and residential programs.

The Illinois Epilepsy Association is the state branch of the Epilepsy Foundation of America, which has an office in Winnetka. The Epilepsy Foundation of America has its national headquarters in Washington, D.C. The organization seeks to prevent the incidence of epilepsy and to maximize the opportunities for epileptics.

The Illinois Society for Autistic Children and the National Society for Autistic Children work to increase the public's awareness of the nature of autism, provide information and lobby for legislation to provide special education designed specifically for autistic children.

The National Association for Down's Syndrome disseminates information, seeks to develop the potential of persons with Down's Syndrome, and encourages research, community acceptance and better programs. The association publishes a newsletter, maintains a speaker's bureau and publishes a selected list of references.

Parents as Planners of Programs

In the 1940's, parents in Illinois were looking for alternatives to placing their mentally retarded children in state or private institutions or to keeping them at home all day. They began five separate demonstration programs to prove to professionals that people who are today labeled "developmentally disabled" could indeed be educated. In 1950, the groups got together to form the Illinois Council for Mental Retardation, forerunner of the Illinois Association for Retarded Citizens.

Early in the 1970's, a group of parents in Lake County thought too few work opportunities existed for developmentally disabled people. Many handicapped adults were failing to reach their full potential because of a lack of training and employment. Under the leadership of John J. Cornell, the parents set up their own business in Highland Park. They called it Opportunity, Inc.

In 1974, two Lake County women with retarded adult sons, Fran Rose and Lorraine Chapman, decided it was time to plan for their children's future away from home. They found out about community living facilities, contacted the state government for money, constructed a building and hired a director. The Moraine Association began housing 20 residents in Fall 1979.

These three examples illustrate the power and influence parents have had in meeting the needs of the developmentally disabled. Educational, training, employment, and residential options for the developmentally disabled are all quite recent (see section on "Philosophy and History," especially the Chapter on Lake County). Someone had to start each of these programs. Someone, perhaps, like you.

If you think there are needs which are not being met and want to do something about it, follow these steps:

1. Check around to make sure the solution to the problem is not being offered. Contact the organizations listed in the directory to find out more about what they do.

2. If you find the need is not being met, talk to other parents whom you think may share your feelings. Find out what they know.

3. If no group or organization is doing what you think is necessary, recruit some parents and get them to help you either:

   - get an existing organization to expand its functions to meet the need you have identified, or

   - establish a new group to meet the need.

Identifying Service Needs

Ask yourself: Is my developmentally disabled child being provided with all the opportunities he or she needs?

The National Association for Retarded Citizens has developed a list of types of services which taken together, form a "comprehensive" network. Can everyone who needs these types of services find them available?

1. Diagnostic and Treatment Clinics. These should be staffed with counselors, educators, nurses, social workers, psychologists, physicians and therapists to diagnose your child's condition.
2. Home Visitation Programs. These "pilot parent" programs help parents in the care and training of their children at home.
3. Parent Counseling. Counseling helps you understand your child's disability and how you can deal with it.
4. Day Training Services. These services are appropriate for severely and profoundly handicapped people. Day training offers education for children.
5. Early Intervention Programs. These train parents and provide diagnostic and therapeutic services.
6. Special Education. Required by law for all children between the ages of 3 and 21.
7. Religious Education. Provides an opportunity for religious involvement at the appropriate developmental stage.
8. Special Recreation. Should be sufficient to allow children to take part in social and recreational activities.
9. Vocational Training and Employment. These services should include evaluation of work skills, vocational training, job placement, and follow-up services.
10. Alternative Living Environments. Options for different types of supervision and assistance as appropriate.
11. Residential Facilities. For temporary or long-term care and education away from home.
12. Citizen Advocacy. Groups and individuals working to safeguard the rights of developmentally disabled people.

13. Research. The goals of research are to prevent disabilities (medical), to develop techniques for maximizing development (educational), and to assess the effectiveness of different environments and delivery systems (social science).

If you have done some background reading, investigated on your own, and found one or more of these services insufficient, you may want to plan to have it offered.

Planning Within Existing Organizations

Not all new ideas require that you set up a new organization. Sometimes it is possible to expand the functions of an existing organization. To do that, however, you first have to become involved in making decisions about the nature and operation of the organization. To build credibility, you need to demonstrate to others that you are serious enough to make the long-range commitment required. This rule applies whether the organization is your school's parent group or your county's major multiple-service planning committee.

Becoming a Board Member

If you want to become a member of the governing board of the organization, begin by attending its meetings as an observer. Learn the issues and the way the board operates. When a vacancy occurs, let it be known that you seek either appointment or election (whichever is the case for your situation) to the board.

As board members, parents work together with program teachers and staff members to decide what kind of educational, therapeutic and work experiences children will receive. Parents are the informed experts on their children, know the ways they want their children to be growing and learning, and know the communities they live in. As a result they have a broad perspective on the needs which should be met for the benefit of their children and families. Professionals and service providers have both overlapping and separate interests. Parents need to ensure policy decisions are based on the needs of children first, not on the needs of organizations.

As a board member, keep in mind that you will be representing not only yourself and your child but also the parents of other children. Keep in mind that you have biases others do not share. Strive to be objective about your child's needs relative to others. To represent other parents well you must solicit their feelings, and ideas on issues being considered. It will also be your responsibility to report to parents about matters under discussion and decisions that have been made. Feedback will be most effective if you schedule time to meet regularly with other parents.

Separate meetings are not particularly necessary. Board members can meet informally with other parents either just before or just after general membership meetings as well as making formal presentations at these meetings.

Board members typically provide functional support for meeting an organization's purposes. That is, board members may be responsible for setting program goals, policy making, hiring and evaluating staff, implementing programs, fund raising, budgeting, publicity, and public relations.

Presenting a Proposal to a Board

Whether or not you are a board member if you want an existing organization to set up a new program or service, you should first set up a planning committee. The committee should prepare a written proposal to present to the organization's governing board.

Here is a list of the kinds of information that might be provided in the proposal:

1. The number of persons in the area to be served who need the program, and the number of be served initially.
2. The age range to be covered.
3. The type(s) and degree(s) of disabilities to be included.
4. The kind or combination of programs to be organized.
5. The location of office and other space required for the program.
6. Staffing for the program, paid and/or volunteer.
7. Costs and sources of funding.
8. Community resources for donations of materials, equipment and labor.
9. Transportation to and from the program.
10. Periodic program evaluation.

The kind of planning implied in the above list will also be required if you decide to set up a new organization rather than working through one which already exists.

Starting A New Organization

Specialists working in Lake County have little trouble identifying needs for additional services for the developmentally disabled. More work opportunities, more community living facilities, more intermediate care facilities, more private schools, more recreation, more skilled nursing centers, more day care ... all of these have been mentioned as needs only partly met at this time.

There are county-wide and regional boards that have an important role in making planning decisions that affect your child's future. Keep members of these boards informed about your organization's progress. Examples of these boards are:

The Lake County Special Education Advisory Committee. Committee members are appointed by the county superintendent of schools to serve in an advisory capacity to the superintendent on special education issues.

The Lake County Developmental Disabilities Planning Committee. The name is a big one, and the committee is too. It has 38 parent, community and agency representatives. Organized in 1976, the committee has worked to develop a comprehensive plan for services for developmentally disabled people. Its priorities include maintaining residential and day care programs, developing a family support unit to help people who need services, and developing employment opportunities in the community.

The fight for recognition and funding of a new organization can be long and hard. Take the example of the Moraine Association described at the start of this Chapter. After getting a number of parents together at a meeting to organize, the association's founders obtained private donations and loans, as well as funding from the Illinois Department of Mental Health and Developmental Disabilities to build a community living facility. The Association later asked the Highland Park City Council to apply for a federal community development block grant for the facility. The Association negotiated a low-interest loan with a local bank backed by the Illinois Health Facilities Authority. It worked with the Lake County Board of Health, the Lake County Department of Mental Health, the Kane, Lake and McHenry Health Systems Agency, and a number of other agencies. "Every golden door has a big mouse trap behind it with lots of paper," said one of Moraine's founders.

The best way to learn how to start a new program is to talk to someone else who has already done it. If you know of a program on which to model your efforts, you job will be easier.

One type of program that has been tried in Lake County and elsewhere is the "pilot parent" program. Such programs are also called "visitation," and "parent outreach," and "parent-to-parent intervention" programs. These programs involve an experienced parent meeting with parents who have just found out their child is developmentally disabled. The experienced parent is not a professional but informally visits with, exchanges information and shares experiences. The experienced parent provides beginning information about what to expect, material to read, and whom to contact. Lake County has one pilot parent program, the Down's Development Counsel, a small group of parents of Down's Syndrome children. Parents of children with other types of developmental disabilities could benefit from similar programs.

Starting a new program is anything but easy. The two most difficult problems you are likely to encounter are gaining community acceptance and raising funds. Resources to assist you in overcoming these and other difficulties are local organizations such as newspapers, radio stations, and service organizations; the United Way, foundations, and county, state and federal governmental agencies. Remain in contact with local and state chapters of national organizations for developmental disabilities. They have had extensive experience and can assist you.

Recommended for Further Reading

Biklen, Douglas. Let Our Children Go: An Organizing Manual for Advocates
1974 and Parents. Syracuse, New York: Human Policy Press.

This manual describes how parents of children with disabilities and their allies can work for their own needs and rights. Six steps are outlined: know yourself before you organize others, alliances, identifying community needs, know those who resist change, learning to use power, and action.

Curry-Rood, Leah, Larry A. Rood, and Sylvia E. Carter. Head Start Parent
1978 Handbook. Mt. Rainier, Maryland: Gryphon House.

This handbook provides a useful introduction to how an organization functions. It covers parent involvement, committees, meetings, funding, and by-laws. Highly recommended for anyone with little organizational experience.

Des Jardins, Charlotte. How to Organize an Effective Parent Group and
1978 Move Bureaucracies. Chicago, Illinois: Co-ordinating Council for Handicapped Children.

Booklet written for parents to show how to get better services for their handicapped children. Describes techniques and strategies for effective lobbying through organized groups, i.e., "parent power."

Du Rand, Lance and John Du Rand. The Affirmative Industry. Minnesota
1978 Diversified Industries, 666 Pelham Boulevard, St. Paul, Minnesota 55114.

An industrial model to provide gainful employment for persons who have handicapping conditions which prevent them from competing successfully in the open job market. The major theme of the manual is the growth of self-sufficiency, both for the industry and the employees. Provides detailed coverage of management, operations, sales and marketing, and finance. Opportunity, Inc. in Highland Park, Illinois was established by parents who used this model.

Fulfilling local, state and federal regulations and soliciting funding involve more information than can be provided here. Here are some broad suggestions for places to start. Write to:

Developmental Disabilities Office Office of Human Development U.S. Department of Health, Education and Welfare Washington, D.C. 20201	Developmental Disabilities Program: The 1975 Amendments
Illinois Department of Mental Health and Developmental Disabilities 401 South Spring Street Springfield, IL 62706	Guidelines for Grants for Community Programs and Standard Application Procedure for Community Programs
United Way of Lake County 2835 Belvidere #201 Waukegan, IL 60085	Request criteria for admission as a participating United Way agency.

Parents as Legal and Legislative Advocates

If you are willing to commit time and energy to the improved well-being of your child and other children, you can become a child advocate. This will involve working with and watching private and government agencies, schools and firms to make sure they meet legal requirements and guarantee the rights your child has under the law.

Education

Educational rights concern more parents of disabled children than any other kind of rights. Thanks to a number of state and federal laws and regulations, your child is entitled to an education as much like that of non-handicapped children as possible.

A federal law, commonly known as Public Law 94-142, the Education for All Handicapped Children Act, requires the public schools to provide an education for your child. This does not mean the education has to be provided in the public schools, however, If your school system lacks the facilities or teachers to meet those needs, the school system must pay to educate your child elsewhere with your approval. But, the school system must make sure that your child is educated in "the least restrictive environment" with as little segregation as possible. The law says your school system may put developmentally disabled children in special classes or special schools only if a child's handicap is severe enough that the child cannot perform satisfactorily in a regular class. The education your child receives must serve his or her needs through the age of 21.

Each exceptional child must have his or her own individualized education program (an I.E.P.). Each year you, the parent, must meet with school officials to draw up an I.E.P. for your child. You may bring friends and professionals to support you during the meeting. Be sure you go through your child's school records before the meeting to be certain they are accurate and up-to-date. The school cannot develop an I.E.P. without you unless you refuse to participate. Together, you and school personnel (for example, teachers, social worker, psychologist, principal, and nurse) develop the I.E.P. It describes how well your child performs in school, what objectives your child should meet in the next year, what specific services your child should get during the school year (for example, speech therapy, physical therapy, and occupational therapy), how much your child may participate in regular classes, and how your child's progress will be measured. One person, usually the teacher, manages your child's I.E.P. throughout the year. If the school decides to take action that will affect your child's placement, it must notify you first. The school must also get your written permission before it can give your child individualized tests or place your child in a special program.

The I.E.P. is important because it is the basis for all of your child's instruction. The school system must make sure that your child gets the services promised in the I.E.P., so you should make sure those services and the goals set for your child are as specific as possible. Do not, for example, settle for a goal of "reading at a higher level" by the end of the school year, but insist on a goal of reading at a specific grade level. Be firm about things that you consider important and do not settle for poor and inadequate service. Keep in mind, however, that the law does not require that anyone be held accountable if your child fails to achieve the growth projected in the I.E.P.'s annual goals and objectives.

For your own protection, keep copies of your correspondence, visits, telephone calls, and all reports relevant to your child's I.E.P. and placement. If you do not agree with something in your child's I.E.P.-- such as your child's placement -- your first step should be to discuss your disagreement with the teacher or other school personnel (such as the social worker, nurse, or principal). They may be receptive to your complaint. If parents object to proposed placement within 10 school days of their receipt of notification of placement, the district shall arrange a conference to resolve the situation. After this conference, if parents still object, they may request a due process hearing.

The due process hearing is your opportunity to be heard by an outside officer not connected with your school system. Make the request for such a hearing in writing. (You may be requesting the hearing more than 10 days after receipt of notification of placement because of a delay caused by the conference.) Send the request by certified mail so that you can be sure it gets to the superintendent. Send copies of your request to your special education director, the Illinois Office of Education, and anyone else whom you think should know about your request.

Once it receives your request, the school district must ask the Illinois Office of Education to appoint an impartial hearing officer. The district must also provide you with information about free or low-cost legal services you may need. Finally, the school district must hold a hearing within 45 days.

Before you go to a due process hearing, visit the program that the school district has offered and take notes to help document why it is inappropriate for your child. You may also want to obtain an outside evaluation from a hospital or clinic with a school psychologist. Get a letter from the hospital or clinic stating why the school's proposed placement is inappropriate, and bring the letter to the hearing.

A careful procedure has been set up to assure that your grievance will be carefully considered at the hearing. You may bring a lawyer or other counsel such as a professional advocate. You may also bring your child and any other person who may provide evidence or relevant information. You will probably want to bring someone with you so you do not feel overwhelmed by the many school professionals who may attend.

You may question school officials, and you can refuse to accept as evidence any information not shown to you at least five days before the hearing. You may obtain access to all relevant records and request a written record of the hearing afterward (the hearings are recorded on tape or by a court reporter). The school district shall require that the hearing be closed to the public. Any question of attendance at the hearing, for example, if you wanted to open the hearing to the public, shall be decided by the hearing office.

Due process hearings are usually informal. A typical hearing officer is not a lawyer, but someone who has worked in special education. Hearing officers usually accept most of the things you want to use as evidence. But you do not have the power to compel someone to attend the hearing.

Two bad things can happen after the hearing. First, the hearing officer may hand down an unfavorable ruling that supports the school's position. Second, and less likely, the school district may fail to change your child's I.E.P. even after the hearing officer tells it to do so. In either case, you may appeal to the Illinois Office of Education. Its lawyers will review your case and recommend action to the head of the office, the state superintendent of education. Law requires that you receive a decision from the Office of Education within 30 days of your appeal.

Ultimately, you can file suit in court. This is a rare last resort, however, and will work only if you first exhausted all the possible administrative appeals.

Throughout all these proceedings, your child will remain in the same educational setting unless you and the school district agree to change it. If you are happy with your child's setting, this will satisfy you. But if you are unhappy, it could mean your child will spend many additional months in an inappropriate setting while you wait for a favorable ruling on your request.

For more information about due process hearings, request the following:

"How to Prepare for a Due Process Hearing", published by the Coordinating Council for Handicapped Children, 407 South Dearborn Street Room 680, Chicago, Illinois 60605.

Law and the Handicapped Child: A Primer for Illinois Parents, available from the Illinois Regional Resource Center, Northern Illinois University, DeKalb, Illinois 60115.

For additional information on these resource centers, see the directory at the back of the manual.

School Records

For your information and for possible future reference, it is a good idea to get copies of school records about your child. Your school should have already notified you of your rights to see these records. You also have the right to obtain copies (usually for the amount it costs to duplicate them). You can attach any statement you wish that adds relevant information, clarifies an issue, or disagrees with the records. You may challenge the records on the basis of accuracy, relevance or propriety. You also have a right to have the records explained to you.

To make changes in the records, notify the superintendent, principal, and/or classroom teacher (again in writing) that you want changes made. If school officials fail to make the changes you want, request a hearing on the records.

The custodian of your child's records must make every effort to insure that they are kept confidential. Information can be released without your written permission under a few conditions, however. For example, the records' custodian of another school may obtain the records if the child will enroll in that school. Information may also be released under court order or in health and safety emergencies. Certain information in school records is classified as "directory information", and this too may be released. Directory information includes name, age, address, academic awards, major field of study, and period of attendance at the school.

When a child reaches the age of eighteen or enrolls in a post-secondary program, he or she assumes the parents' rights of access and confidentiality. Unless the parents act to retain legal responsibilities for the child, the rights outlined above no longer belong to them. (See section on guardianships under Social Services).

Finally, laws also protect educational rights of your child. Tests or evaluations, for example, cannot discriminate on the basis of race, culture, or language. The evaluator must know your child's language or use an interpreter.

In post-secondary education, federal regulations prohibit discrimination solely on the basis of a handicap in the recruitment, admission and treatment of people in educational programs.

The State Board of Education has published a free booklet that concisely describes your educational rights and those of your child. The booklet also provides a sample letter to request a due process hearing. Write for "The Educational Rights of Handicapped Children", available from the State Board of Education, Illinois Office of Education, 100 North First Street, Springfield, Illinois 62777.

Developmentally disabled children have specific legal rights not only in education, but also in health, employment, voting, driving, and other areas.

Health

They are entitled to all medical services and medically-related instruction that hospitals provide to the public. Hospitals must provide an emergency room interpreter or make other provisions for deaf patients. Mentally retarded people may seek and receive birth control information from doctors.

Although developmentally disabled people should have the legal right to be voluntarily sterilized, in practice they do not. This is because doctors, who perform the sterilization, and the judges, who may authorize it, often do not think that such a person can give informed consent to sterilization, and they are reluctant to allow a guardian or other person to consent for the disabled person. Federal regulations prohibit the use of federal Medicaid money to sterilize adults who do not voluntarily give their consent, and they prohibit use of such money for sterilization of any minors. Involuntary sterilization is prohibited by the law.

Employment

Developmentally disabled people also have the right not to suffer discrimination in employment. The disability must not be considered by the employer unless it prevents the job from being done adequately. In fact, employers must make a "reasonable accommodation to the known physical and mental limitations of a handicapped applicant or employee" unless they can demonstrate that such accommodations create an undue hardship on the employer. "Reasonable accommodations" may include modified work schedules, the purchase of new equipment, and the provision of readers or interpreters. Firms that do business with the United States Government must take affirmative action to hire and promote disabled people. Finally, state and federal laws and regulations prohibit discrimination against qualified people in hiring, firing, compensation, fringe benefits and any other terms of employment. Suspected discrimination may be reported to the U. S. Department of Labor, 230 South Dearborn Street, Chicago, Illinois 60604, or to the Illinois Fair Employment Practices Commission, 179 West Washington Street, Chicago, Illinois 60602.

Voting

Disabled people 18 or older also have the right to vote. They register to vote at their local township or city hall. If they are homebound, they can call their local municipal government office to arrange for voter registration at home. They may arrange for help in casting votes on election day. If they cannot visit the polls on election day, they may vote by mail if they first apply to the county clerk for an absentee ballot. They may also apply to the county clerk for a disabled voter's card, which will allow them to vote by absentee ballot without a physician's certificate each year for five years. The Lake County Clerk's office is in the County Building, 18 North County Road, Waukegan, telephone 689-6660.

Driving Privileges

Physically and mentally handicapped people 16 and older may or may not have the right to drive. The Illinois Secretary of State has the power to refuse a driver's license to anyone he believes may not operate a vehicle safely. Licensed drivers, however, may request special registration plates exempting their cars from time limitations on parking in business districts and entitling them to use specially marked parking spaces. Contact the

Registration Title Division, Office of the Secretary of State, State of Illinois Building, Chicago, Illinois 60601.

Also, handicapped car owners are protected under state law from being charged higher insurance rates by insurance companies. People treated unfairly in this way should contact the Consumer Complaint Division, Illinois Department of Insurance, 160 North LaSalle Street, Chicago, Illinois 60601.

Public Transportation

Handicapped people also have rights with respect to other forms of transportation. Law requires that new mass transportation services make a special effort to accommodate handicapped people. New mass transit projects using federal funds can charge handicapped people no more than one-half the normal fare during non-peak hours. Call the Regional Transportation Authority (RTA) at 836-7000 for information on how to obtain a special identification card that allows handicapped persons to take advantage of the lower fares. For information about federal policies on transportation, contact the Department of Transportation, Office of Environmental Affairs, 400 Seventh Street S.W., Washington, D.C. 10590.

Federal law requires that Amtrak, the national passenger railroad, ensure that handicapped people are not denied inter-city service and to see that they get special assistance to get on the trains. (Amtrak has no stops in Lake County, though.) Airlines are not required to serve handicapped people whom the airlines think may pose a danger to themselves or others. The rights of handicapped to transportation are being strengthened year by year, but still have a way to go.

Residents of Institutions

People living in public and private residential care institutions retain many of the rights of non-institutionalized people under the Illinois Mental Health Code. Unless a court declares them incapable, they may vote, retain a driver's license, marry, make a will, sign contracts, and manage their own affairs. They also have rights regarding treatment, communication with outsiders, information about their hospitalization, and other aspects of institutional life. The institutions are prohibited from using restraints or seclusion as punishment or discipline except to prevent residents from causing physical harm to themselves or others. Residents may refuse treatment, retain and use personal property, perform labor for wages, use their personal funds as they wish, and receive treatment in the "least restrictive setting". The Rights Handbook for Handicapped Children and Adults, provides a thorough description of those rights. This booklet is available from the Coordinating Council for Handicapped Children, 407 South Dearborn Street, Room 680, Chicago, Illinois 60605.

Access

Architectural barriers create a major problem for many developmentally disabled people, especially those in wheelchairs. Barriers prohibit such people from making use of a particular building or service. Typical barriers are stairs and narrow doorways.

Under Section 504 of the Federal Rehabilitation Act of 1973, schools, agencies and employers must make a "reasonable accommodation" to the needs of the handicapped. Under the Federal Architectural Barriers Act of 1968, new non-residential buildings built with any federal funds must be accessible to the handicapped. In general, the law means that handicapped people must at least be able to get to, and to get inside, the building. Curbs, sidewalks, and entrances must permit wheelchairs to pass. In schools, the law means that handicapped children should have full access to educational programs. Schools, agencies and businesses have until 1981 in many cases to make their facilities accessible.

A state law passed in 1968 requires that buildings owned or leased by the State of Illinois meet minimum accessibility requirements, but many such buildings still do not. The law provides no means for enforcement.

A 1975 addition to Illinois' Facilities for the Handicapped Act requires that at least the first floor of all new public buildings also meet standards for accessibility. Public buildings include privately-owned buildings that serve the public, such as restaurants, hotels, theaters, and office buildings. They do not, however, include one- and two-family homes. The standards for accessibility require ramps, handrails, elevators, wide doors and other conveniences or designs necessary to allow handicapped people to enjoy use of a building. This law, unlike the 1968 law concerning only state buildings, carries a fine of $100 per day for violations.

Economic Welfare

Developmentally disabled people can take advantage of a number of government programs designed to promote economic security and make the costs of living more reasonable.

Under federal law, handicapped people can apply for financial aid to help with rent. Contact the Chicago office of the U. S. Department of Housing and Urban Development at One North Dearborn Street, Chicago, Illinois, telephone 353-5880.

Tax laws provide for deductions for the cost of special education, lodgings, and medical services. For more information, contact the Internal Revenue Service office at 2720 West Grand Avenue, Waukegan, Illinois, at their toll-free number, 800-972-5400. You can request a Tax Fact Sheet by sending a stamped, self-addressed envelope to the Coordinating Council for Handicapped Children, 407 South Dearborn Street Room 680, Chicago, Illinois 60605. (The Coordinating Council also provides a fact sheet on Supplemental Security Income, SSI.)

For parents with children in residential care institutions or homes, Illinois provides financial aid under its Individual Care Grant Program. Parents pay no more than $100 per month for residential care, no matter how much the parents earn. For information about this program, contact the Elgin office of the Illinois Department of Mental Health and

Developmental Disabilities at 750 South State Street, Elgin, Illinois 60120, telephone 742-1040.

The Illinois Division of Vocational Rehabilitation provides help for job training, counseling and other services. The division has an office at 4617 Grand Avenue, Gurnee, Illinois 60031. The federal government also provides welfare-related services for disabled people. Supplemental Security Income (SSI) is available to many children at home or in private institutions, and regular social security benefits are available if the parents are on social security or if the child is over 22. Lake County applicants should go to the Social Security Office, 2500 Grand Avenue, Waukegan, Illinois 60085, telephone 244-5050.

Unfortunately, earning money sometimes disqualifies disabled people from SSI and other benefits. Some people in sheltered workshops, for example, earn enough money to disqualify themselves from SSI. Disabled people on social security may also lose some benefits by living at home with their parents, even though social security provides too little money for them to live independently. As a child advocate, you may wish to help lobby for legislation to help remedy these situations. Talk to the people in your local parents' group or contact the Coordinating Council for Handicapped Children (see listing at the back of this manual) to see what you might do.

Advocacy

The function of child advocacy is not to provide the "services" necessary for healthy growth and development. The function of child advocacy is to see that children do receive services from whomever should be held responsible for providing them. As a parent you probably naturally already provide both a service function and an advocacy function even though you may not realize it. If you help your child learn a task, you are providing an educational service. If you check with your child's teacher or therapist about your child's ability in some area, you are acting as your child's advocate. This example illustrates the difference between service and advocacy. "Service" is providing children with something they need, whether it is food, clothing, education, training, or recreation. "Advocacy" involves checking to see that children are receiving the service.

The process from being concerned about services your child receives to being concerned about services for all developmentally disabled persons will get you involved in advocacy at the local and state levels (and perhaps by extension at the national level as well). Good government does not just happen by chance. You will need to work to elect officials who support the need for community-based services and to provide written support for the passage of necessary ordinances and legislation.

Obtaining Local Support

The local city, township and county governments provide avenues of influence which parents can access to advocate for the developmentally disabled. As an organized group or as individuals, parents can approach these local governments to gain support for a variety of issues. For example, parents in a neighborhood could ask the local government for assistance to make the local park's equipment safe and usable by all children. An organized group of parents could approach local governments for financial assistance to improve or start programs within the community.

Local governments have the responsibility and the resources to listen and act upon issues raised by the citizens. Local governments tax their citizens to provide specified services (such as education and recreation) and administer funding from the state and federal governments for local projects.

To understand the functions of local governments you should attend meetings open to the public. Get a feeling for degree of support for your cause by familiarizing your elected representative with your ideas and feelings, and by talking with government officials (such as planning departments, zoning boards and school board officials). Meet with other citizen groups who are regularly involved in the local governments, for example the League of Women Voters. Perhaps, your group may be able to present the plans and concerns to the local government bodies. Getting an advisory board or commission recognized can be a good way to open debate.

Influencing State Legislation

Before becoming concerned about developmentally disabled children, many parents have had little idea how government operated. Because of their concern they now watch for all legislation concerning the handicapped. They know their elected representatives from the House and the Senate. This change does not occur overnight but one step at a time. Begin by finding out all you can about existing and pending legislation covering the service need that concerns you most.

The appendix to the end of this chapter contains information on newsletters and organizations that monitor state legislation and state departments' policies. Contact organizations concerned with the rights of the developmentally disabled for further information as to which legislators and state departments might be helpful with your concerns.

The legislative process is usually time consuming. In order to get a proposal to become law, keep working at the local level with interested groups and state officials throughout the process.

A Bill may originate in either House or Senate, and the procedure is nearly identical in each Chamber, although changes in procedures will occasionally occur through various means including unanimous consent or a favorable vote on suspension of rules. Deadlines for each step in the bill process are established by each Chamber's rules.

The progressive steps in the passage of a bill are:

- A Bill is introduced, assigned a number, first read in Chamber and printed.
- The Bill is then assigned to a standing committee (by the Committee on Assignment of Bills).
- The Committee considers the Bill in a Public Hearing.
- The Committee may report to the Chamber "Do Pass," or "Do Pass as Amended."
- Or the Committee may report "Do Not Pass," in which case the Bill is usually dead.
- If still alive the Bill then is placed on the Calendar of the Chamber for 2nd Reading for vote on Amendments from the Committee or the Floor. (Amendments adopted in House Committees do not require a floor vote.)
- If the 2nd Reading is called with no Amendments offered to the Bill, it moves to 3rd Reading position.
- If Amendments are offered, they are adopted or rejected.
- The Bill is then placed on 3rd Reading for final vote.
- If Bill receives a majority vote (89 House, 30 Senate) it is placed on the Calendar of the other Chamber and the entire process is repeated.
- If the Bill fails to receive a majority vote it is dead.
- If the Bill receives a majority vote in both houses, it then goes to the Governor.
- Governor acts to approve, veto, reduce or line veto, or amendatory veto.
- If approved, Bill is assigned a Public Act number.

Recommended for Further Reading

To keep abreast of all the happenings in the field of developmental disabilities there is one book and several organizational newsletters that we recommend:

Bureau of Community Health Services
Health Services Administration
Public Health Service
U.S. Dept. of Health, Education and Welfare
Rockville, MD 20857

Ask for DHEW Publication
(HSA) 77-5290
A Reader's Guide for Parents of Children with Mental, Physical, or Emotional Disabilities by Coralie B. Moore and Kathryn G. Morton
Maryland Association for Retarded Citizens

Includes annotated bibliography of books relevant to all handicaps, and to specific handicaps. Contains suggested books for children about children with handicaps. Lists organizations, directories and agencies.

C.C.H.C. Newsletter. Coordinating Council for Handicapped Children, 407 S. Dearborn Room 680, Chicago, IL 60605. Monthly newsletter for Chicago metropolitan area informing subscribers on recent legislation, coming events, and pertinent information on advocacy for the handicapped.

Common Sense from Closer Look. Parents' Campaign for Handicapped Children and Youth, Box 1492, Washington, D.C. 20013. Quarterly newsletter for parents of handicapped children informing them of their legal rights and new programs around the country.

D.D. Directions. Illinois Governor's Planning Council on Developmental Disabilities, 222 South College Street, Springfield, IL 62706. Bimonthly newsletter designed to inform and educate interested persons and agencies about the purposes and activities of the Council, its regional councils, and other organizations as they relate to the Council.

Feelings. Illinois Department of Mental Health and Developmental Disabilities, 160 N. LaSalle St., Chicago, IL 60601. Bimonthly newsletter designed to educate and inform Department personnel and others about the purposes and activities of the Department and their linkage to community-based programs.

The IDDAA Advocate. Illinois Developmental Disabilities Advocacy Authority, One West Old State Capitol Plaza, Suite 917, Springfield, IL 62701. Bimonthly newsletter covers issues, concerns, and developments in protection and advocacy services of and for the developmentally disabled of Illinois.

P.C.M.R. Newsbreak. President's Committee on Mental Retardation, Washington, D.C. 20201. Monthly capsulized information on interesting programs and information for the handicapped around the Country.

THE DEVELOPMENTAL DISABILITIES

Is it important to have a definition for developmental disabilities? Recent court battles over the legal rights of the handicapped have recognized that the developmentally disabled have the same legal rights as all of us do. These human priviledges include: the right to citizenship, equal protection under the law, an education, and treatment. We need to define what we mean by developmental disabilities, in order to separate the children who need these services from those who do not. However, we must remember not to structure our feelings towards the child around a definition which is used by professionals for professional reasons. Definitions change over time, and from place to place. The definition used will provide children with the services they need. Sometimes children are labelled mentally retarded, for example, and are in programs which are specially geared towards that label, but the minute these children leave school in the afternoon, they play and run around with the rest of the neighborhood children. These children are called the "six-hour retarded children", since it is only during those hours that they need the special services. "Good" labels open doors to needed services. "Bad" labels put children into inferior programs which cause discouragement for child and family. But NO label provides NO service, so it is important for parents to see where their children might fit in.

When our project was undertaken, in the Summer of 1977, developmental disabilities were defined as meaning a disability of a person attributable to mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of these conditions. A Chapter for each of the four categories of developmental disabilities -- Mental Retardation, Cerebral Palsy, Epilepsy, Autism -- provides a descriptive definition, discusses the incidence of the disability in the population, explains known and hypothesized causes, identifies symptoms, outlines the current range of medical treatments and educational programs, suggests directions for further research, and provides referrals to specialized literature and organizations.

While labels can provide protection and services, negative stereotypes may also be associated with labels. Throughout the history of special education the labels have been changed in an endeavor to replace perjorative value judgements with nonevaluative classifications. For example, the terms "idiot", and "moron" are never used now by caring persons although at the turn of the century they were acceptable professional terminology.

The Chapter on Noncategorical Definitions discusses recent recommendations for a definition of developmental disabilities without the use of labels. Optimistically, a non-categorical definition should continue to cover the same individuals as the previous definition and add other individuals with similar characteristics. That is, the new definition should provide broader coverage. Pessimistically, the effect of dropping all identifiable categories of disability from the definition could be to create a situation of ambiguity which permits evasion of responsibility. Monitoring and advocacy are likely to become even more important to guarantee continuation of and improvement in services.

Mental Retardation

Mental retardation is a condition which prevents the brain from developing to its full potential. It is not a disease, nor should it be confused with mental illness. Mental retardation describes many levels of behavioral performance, and no two mentally retarded individuals are affected in the same way. It is important to remember that just like each of us, a mentally retarded child is a unique person. There is no one explanation for mental retardation, no one behavioral pattern that the child exhibits, and no set way for parents to experience their mentally retarded child.

Mentally retarded children mature more slowly, and have a more difficult time learning than normal children do. Their scores on tests which measure general intelligence are low. The most common intelligence tests are called IQ tests. Children who score below 70 on these tests are often defined as mentally retarded; meaning 97 percent of the population have higher IQ scores.

IQ scores however, are not the only way in which mental retardation is determined. Just as important is a person's adaptive behavior, that is, the person's ability to function on a day-to-day basis, in interaction with others, and self maintenance (see table below). Mentally retarded children have difficulty in learning adaptive behaviors. The degree to which children have difficulty in mastering these skills, together with their general IQ scores, determine whether or not they will be labelled mentally retarded.

Development of Adaptive Behaviors

During infancy and early childhood:

1. Development of movement and perception (sensorimotor skills)
2. Speech and language (communicative skills)
3. Toilet training, eating, dressing oneself (self-help skills)
4. Learning to interact with others (socialization)

During early childhood and adolescence:

5. Application of academic skills to daily life activities (for example, ability to use money, read signs, write a message)
6. Using reasoning and judgement (for example, there is snow outside, so it must be wintertime)
7. Social skills (participation in group activities, making friends)

During late adolescence and adult life:

8. Vocational and social responsibilities (caring for oneself, having a job, home, and family)

Why is it important to have a definition for mental retardation? Recent court battles over the legal rights of the handicapped have recognized that the mentally retarded have the same legal rights as all of us do. These human priviledges include: the right to citizenship, equal protection under the law, an education, and treatment. We need to define what we mean by mental retardation, in order to separate the children who need these services from those who do not. However, we must remember not to structure our feelings towards the child around a definition which is used by the professionals for professional reasons. Definitions will change over time, and from place to place. The definition you use will provide your child with the services he or she needs. Sometimes children are labelled mentally retarded, and are in programs which are specially geared towards that label, but the minute they leave school in the afternoon, they play and run around with the rest of the neighborhood children. Such a child is called a "six-hour retarded child", since it is only during school hours that special services are needed. "Good" labels open doors to needed services. "Bad" labels put children into inferior programs which cause discouragement for child and family. But NO Label provides NO service, so it is important to see where your child might fit in.

Estimates vary as to how many people in the United States are mentally retarded. Three out of every hundred -- or currently 6.3 million persons--will be regarded as retarded at some time in their lives. One percent--or 2.1 million people--can be considered as retarded at any particular time; for example, right now. The difference in numbers is due to the issue of whether a person who has overcome handicaps should be considered retarded. Most retarded persons are mildly retarded, meaning they are able with help to function with a high degree of independence and individuality. The number of retarded persons who can be classed as mildly retarded ranges, on the average, between seven and a half to nine persons out of 10.

Mental retardation can strike individuals of every race, religion, nationality, and social and economic background. President Kennedy, who had a mentally retarded sister, exposed the issues of the mentally retarded to the public. Today, one out of every 10 Americans has a member of the family who is mentally retarded. Parents' groups have been the pioneers in fighting for the rights of the mentally retarded, and are working to insure that proper programs and facilities are made available.

Causes of Mental Retardation

There are now more than 250 identified causes of mental retardation, but many more are unknown, or not fully understood. Any factors which may disturb brain development before, during or after childbirth, or in early infancy can cause mental retardation. In this section we will discuss some of the more common causes of mental retardation.

Genetic Irregularities

The human body is made up of millions of tiny cells which are the basic units of life. Each cell in the human body, except for those which are in the reproductive cells (the egg or ovum and the sperm), has 46 chromosomes which are arranged into 23 pairs. The chromosomes in each of these pairs carry information about human traits. This information is carried on hundreds of genes, which cover the chromosomes. They are microscopic units of information. The information carried on all of the genes from the different chromosomes combines to form the genetic code. The genetic code holds information which determines everything about us--the color of our hair, how fast we will grow, the size and shape of our fingernails, thumbs, arms, and so on.

The genetic code for each of us was determined when the sperm and ovum from our parents united and formed a zygote. This occured at fertilization. Our reproductive cells are unique in that they carry half of the chromosomes (one from each pair) that every other cell carries. Thus, when the two reproductive cells unite, each parent cell contributes to the genetic code of the new zygote. It is this new, unique code which determines the growth and development of the child.

One pair of the 46 chromosomes carries the information which determines sex. In females this pair is composed of two X chromosomes. In males this pair is composed of an X and a Y chromosome. Thus, in the reproductive cells, where the chromosome pairs are split up, the ovum can only have an X for its 23rd chromosome, whereas the sperm cells can have either X's or Y's. The Y chromosome carries very few genes. Its main function is to decide the sex of the child. The X chromosomes on the other hand, are loaded with information that determines other traits. Genes on chromosomes will be either "dominant" or "recessive". The dominant genes may be thought of as pushy in character, whereas the recessive genes are weak. When the genetic code is formed during fertilization, the stronger genes take over, and allow only their information into the genetic code. In males, where the 23rd pair of chromosomes is XY, the genes on the X chromosome have none on the Y chromosome to compete with, so they put all of their information into the code. Sometimes, the information which goes into the code is faulty. One type of genetic irregularity occurs when there is a faulty recessive gene on the sex determining chromosome. Since there is no information on the Y chromosome to counteract the faulty message, boys will get the faulty information. Girls can only get the faulty information if the father also carries the faulty gene. An example of a disorder that is caused by a faulty, recessive, sex-determining gene is Phenylketonuria (PKU). It occurs in about one in 20,000 births. The faulty gene in this case causes the absence of a substance which breaks down certain types of proteins, some of which are found in milk. An infant who has PKU cannot break down the proteins that are found in milk, and starts to accumulate a type of acid (Phenylpyruvic acid) which has a damaging effect on the developing nervous system. PKU is a disorder which is determined genetically at fertilization, but the degree of damage that occurs depends on what happens after birth. (See section on Nutrition in Chapter on Health Care Services.)

Chromosomes are like tiny threads, and occasionally they can become injured. Most of the time when this happens the cell cannot survive, but at times a new type of gene appears. This is called a mutant gene. Chromosomes can also come in abnormal numbers or structures. The genetic code in all of these irregular chromosomes has been altered. An example of a disorder caused by this type of genetic irregularity is Down's Syndrome. Down's Syndrome was the single most common cause of mental retardation, affecting one in 770 babies born each year. Recent evidence seems to indicate the incidence is decreasing.

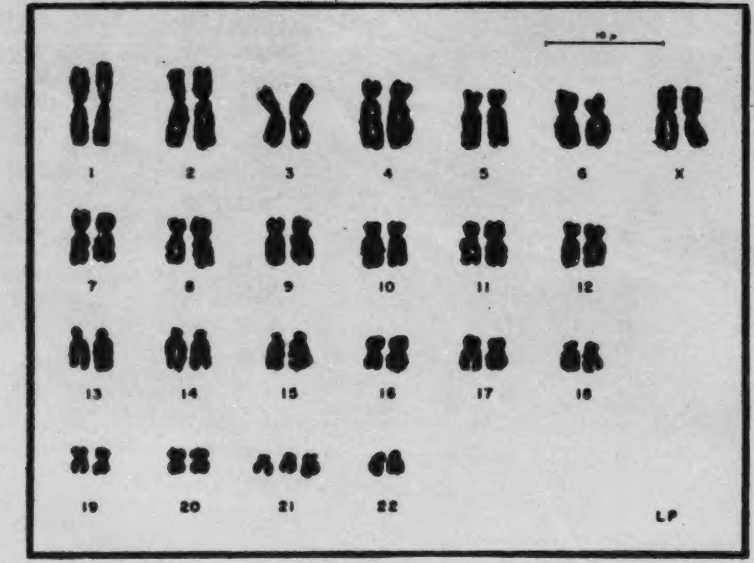
A newborn baby with Down's Syndrome usually has certain physical features recognizable to an experienced doctor or nurse but often not obvious to others. Appearance is a concern of many parents. The presence of the extra chromosome alters normal development. This alteration results in the physical features characteristic of Down's Syndrome. Most of the babies do not have all of these features but some of the many signs may be apparent. For example, the eyes may slant upward, the ears may be small, the tongue may stick out, the hands may be smaller with a single crease across the palm and the little finger turned in, and the feet may have a wider space between the big toe and the other toes. The overall size of the body, and the head in particular, may be smaller, and the baby is often more floppy and less active than other babies

One of three known explanations for Down's Syndrome is that there is an extra chromosome present in the 21st pair (normally, each of the 23 pairs have two chromosomes). This results from faulty distribution of the chromosomes during formation of the egg or sperm. This mistake occurs before conception, and is sometimes called trisomy 21. It explains about 90% of the Down's Syndrome cases. (See diagrams on following page.)

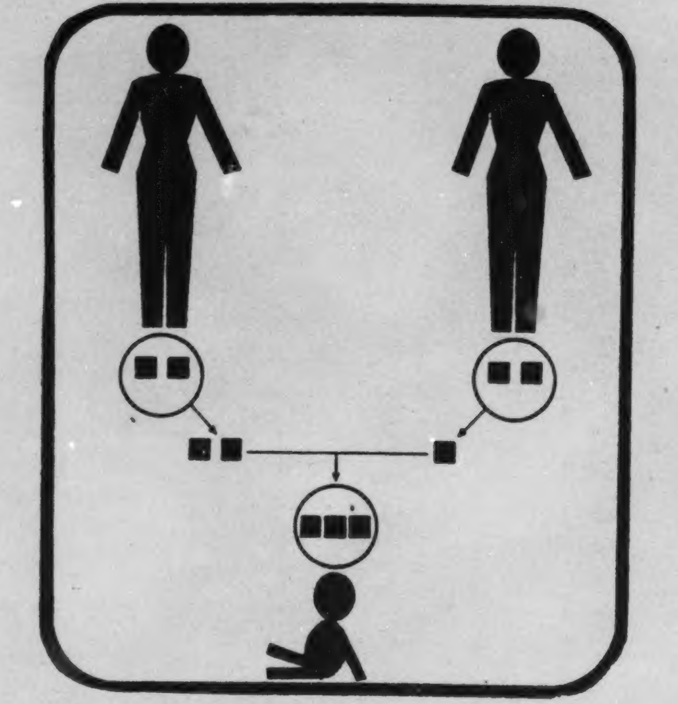
The faulty chromosome may come from either mother or father. The chances of contributing an extra chromosome become greater when the parents are older. For this reason, amniocentesis is increasingly recommended to pregnant women over the age of 35 (see Section on Genetic Counseling).

Two other causes of Down's Syndrome explain the remaining four to five percent of the cases. One occurs after the egg and sperm unite, and begin to develop into an embryo. The disorder results from division of the growing, multiplying cells. The degree to which the characteristic Down's Syndrome traits are present in the child, depends upon the number of the divisions that have already taken place in the zygote. If the mistake occurs after many divisions, and there are plenty of normal cells formed already, then the abnormalities in the child's behavior and appearance tend to be less severe.

The last and most rare case of Down's Syndrome occurs when a chromosome or a part of a ripped chromosome becomes attached to another chromosome. This is called translocation. The Down's Syndrome child carries the normal pair of chromosomes in pair number 21, along with the extra translocated chromosome. One or both of the parents of these children may be carriers, and this happens in one third of the translocation cases. The other two thirds result from translocation that occured after fertilization.



Cell division resulting in an abnormal chromosome number (47) as seen in Down's Syndrome. Reproduced from page 33 of the Third Edition of Mental Retardation, published by the American Medical Association, 1976.



The drawing above shows what happens with one pair (the 21st pair) of chromosomes. The squares represent the chromosomes. In the case of Down's syndrome, a mistake occurs. The egg from which the baby develops receives two chromosomes of the 21st pair from one of the parents and one chromosome 21 from the other parent, giving the baby an extra chromosome. Therefore, a baby with Down's syndrome has a total of 47 chromosomes in every cell in the body.

Problems During Pregnancy

Blood incompatibility can be another cause of mental retardation. Red blood cells contain certain kinds of proteins on their surface. One of these is called the Rh protein. It acts as a foreign protein when it enters the blood of a person who does not have that same protein. If a mother has Rh negative blood (blood which does not have the Rh protein) and Rh positive blood (blood which has the Rh protein) is introduced to her system, her body responds by producing antibodies which kill the Rh positive blood cells. This can happen during a blood transfusion, or during the delivery of a baby who has Rh positive blood. The first born baby is not hurt by the blood incompatibility. If the mother's Rh negative system was permitted to build up antibodies, future pregnancies could result in brain damage to the fetus because of the destruction of the fetus' Rh positive cells.

Today, Rh negative mothers are treated after giving birth to Rh positive babies. An immunization is given to the mother which destroys the Rh positive blood cells in her body, before her system has a chance to develop antibodies against them.

Mental retardation of a prenatal origin is the most common of all birth defects. Malnutrition, viruses, infections, and many other illnesses and traumas during pregnancy may result in a child being born retarded. (See Chapter on Considerations about Having More Children.)

Problems at Birth

There are also many factors which can increase the risk of mental retardation during delivery. Any cause of extreme pressure on the infant's head during delivery increases the risk of brain damage. Conditions, such as the position of the infant, the size of the infant's head in relation to the dimensions of the mother's pelvis, the amount of time required for delivery, and the supply of oxygen and nutrients to the infant during delivery, may cause mental retardation.

Prematurity, though not a direct cause of mental retardation, is associated with low birthweight, which in turn is associated with mental retardation. Postmature babies, born 14 or more days after the full term of 40 weeks, occur in about 4% of all pregnancies. Although some fetuses are completely unaffected by postmaturity, others starve because of the slowing down of the food supply in the placenta. Here again, the concern is with the adequate supply of oxygen to the infant's brain.

Asphyxia is a medical term which means that loss of consciousness occurs from not enough oxygen being supplied to the brain. Whenever the brain is deprived of oxygen, the potential for brain damage exists. Possible causes for asphyxia are: separation of the placenta from the womb before completion of the birth process, an overdosage of oxytocin (a hormone used to induce labor), usage of other drugs (such as depressants or sedatives), usage of anesthesia (to relieve pain during childbirth), or malformation of the baby's lungs. Too much oxygen intake can also be hazardous for the baby. Premature babies are sensitive to "pure" oxygen (over 40% levels). Before this was known, premature infants were blinded and some became mentally retarded as a result of an overdosage of pure oxygen.

Problems After Birth

A newborn baby is a tiny, growing individual, whose immature brain is more vulnerable to disease and injury than the mature brain. Infections at birth or shortly after are another possible cause of mental retardation. Meningitis is an inflamation of the brain lining due to infection. It can occur before the baby is born, during labor, delivery, or soon after birth. Meningitis is life threatening, but can be treated. It is most dangerous to the baby under one year of age. Inflammation of the brain itself is called encephalitis. It most commonly occurs in infancy, as a result of mumps, measles, or chicken pox, and may result in mental retardation.

Severe head injury can also cause brain damage in children. These types of injuries are most commonly caused today by accidents. In general, injury due to infection is much more severe than that caused by a single accident. Also, injuries that occur to children who have already begun to walk and speak are usually less severe and result in different developmental problems than those which occur to younger children.

Levels of Mental Retardation

About 89% of mentally retarded children are mildly retarded, and not noticeably different from the rest of their peers. Sometimes these children are not even diagnosed as being mentally retarded before they start school. For these children, the label "mentally retarded" arises only in the context of school, as a result of academic failure. The adaptive behavior of these children is normal. Although they might be slow learners in school, they often excell in non-academic skills. (Some of them are the "six-hour retarded children" referred to in the introduction to this Chapter.)

Moderately retarded children account for about 6% of the mentally retarded population. Their handicap is usually diagnosed before they enter school. These children have noticeable delays in achieving developmental milestones, such as rolling over, sitting up, crawling, and learning to speak. An early intervention program can minimize the delays. With continued appropriate education at home and school, they learn to care for themselves, and acquire the skills necessary for employment.

Severely and profoundly retarded children make up the remaining 5% of the mentally retarded population. Often they exhibit other handicaps in addition to their severe intellectual deficits, such as: blindness, deafness, cerebral palsy, or epilepsy. With the appropriate education, many severely and profoundly retarded individuals can learn to care for their basic needs.

Sometimes children who are really mildly retarded are labelled as having a learning disability. The distinction between a learning disability and mental retardation is that children with learning disabilities have IQ scores in the normal range (70 and above on the Stanford-Binet and Cattell tests) but demonstrate unevenness in their pattern of learning abilities. In contrast, mentally retarded children have a "general learning disability" affecting all learning abilities. The distinction between the two disabilities may be difficult. Correct diagnosis and assessment, and therefore appropriate educational placement, is dependent upon the expertise of the clinic or school personnel (see Chapter on Diagnosis and Assessment).

Levels of Mental Retardation

Level	Age 0-5--maturation and development	Age 6-21--training and education	Adult--social and vocational adequacy
Mild ..... IQ: 52-67 89%	Often not noticed as retarded by casual observer, but is slower to walk, feed self, and talk than most children.	Can acquire practical skills and useful reading and arithmetic with special education. Can learn to get along socially.	Can usually achieve social and vocational skills adequate for self-maintenance; may need occasional guidance and support when under unusual social or economic stress.
Moderate .... IQ: 36-51 6%	Noticeable delays in motor development, especially in speech; responds to training in various self-help activities.	Can learn simple communication, elementary health and safety habits, and simple manual skills; does not progress far in functional reading or arithmetic.	Can perform simple tasks in a supportive work environment; participates in special and family recreation; travels alone in familiar places; usually requires ongoing support for self-maintenance.
Severe ..... IQ: 20-35 3.5%	Marked delay in motor development; little or no communication skills; may respond to training in elementary self-help, e.g. self-feeding.	Usually walks barring specific disability; has some understanding of speech and some response; can profit from systematic habit training.	Can conform to daily routines and repetitive activities; needs continuing direction and supervision in protective environment.
Profound ..... IQ: 19 and below 1.5%	Gross retardation; minimal capacity for functioning in sensori-motor areas; needs nursing care.	Obvious delays in all areas of development; shows basic emotional responses; may respond to skillful training in use of legs, hands, and jaws; need supervision.	May walk, need nursing care, have primitive speech; usually benefits from regular physical activity; incapable of self-maintenance.

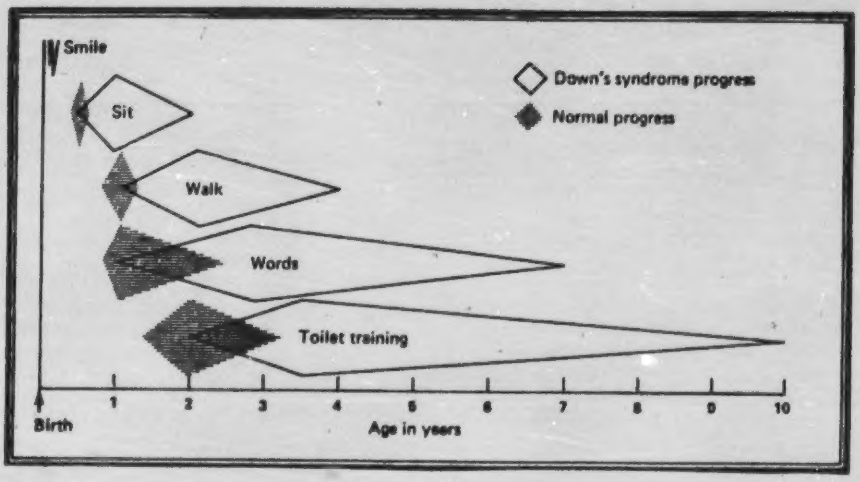
Adopted from the President's Panel on Mental Retardation. A National Plan for a National Problem: Chart Book, U.S. Department of Health, Education and Welfare, Washington, D.C., 1963, p. 15. The four levels of mental retardation are translated into IQ ranges for the Stanford-Binet and Cattell intelligence tests as reported on page 19 of the American Association on Mental Deficiency's 1977 Edition of the Manual on Terminology and Classification in Mental Retardation.

Identification

Parents anxiously await for their newborns' first signs of growth. They keep close watch for the baby's first smile, first words, first step. These first signs are of especially vital importance for parents of developmentally disabled children. Every child grows and develops at a different rate and may develop faster in some areas than others. But there are certain milestones that must be reached before the baby can develop further. You need to watch for and keep a record of these milestones so that you are aware of any delays which may exist. Developmentally disabled children will have delays in several major areas. You need to know where the delays exist, so that you can work on developing the skills needed to reach each milestone.

In the Chapter on Parents and the Needs of Their Children we have listed certain areas in which parents of developmentally disabled children should focus their efforts to develop their child's skills. Also see the following page for early signs that a developmental disability may exist.

Mental retardation is an irreversible condition. Mentally retarded children will be behind their normal peers in reaching many of the developmental milestones. For example see the chart below which illustrates the range of development of normal and Down's syndrome children. The child with mental retardation has the power of potential. Each child has certain skills which can be developed under the right conditinns. It is crucial to provide the opportunity for development of these skills, and to encourage your child each step along the way.



Early development of Down's syndrome children living at home compared to that of normal children. The widest point in each diamond represents the average age of attainment and the spread of the diamonds represents the range. (From Nancy M. Robinson and Halbert B. Robinson, The Mentally Retarded Child, Second Edition, New York: McGraw-Hill, 1976, page 87.)

Early Signs That a Developmental Disability May Exist

--SEEING

If Your Child...

- does not blink or turn head away from bright lights by 2 months...
- frequently rubs eyes...
- has reddened, watering or encrusted eyelids...
- crosses one or both eyes...
- holds head in an unnatural position when looking at something...

--MOVING

If Your Child...

- is unable to sit up without support by age 1...
- cannot walk without help by age 2...
- does not walk up and down steps by age 3...
- is unable to balance on one foot for a short time by age 4...
- cannot throw a ball overhand and catch a large ball bounced to him/her by age 5...

--PLAYING

If Your Child...

- does not play games such as peek-a-boo, patty cake, waving bye-bye by age 1...
- does not imitate parents doing routine household chores by age 2 to 3...
- does not enjoy playing alone with toys, pots and pans, sand, etc. by age 3...
- does not play group games such as hide-and-seek, tag-ball, etc. with other children by age 4...
- does not share and take turns by age 5...

--HEARING

If Your Child...

- does not turn toward sounds by 2 months...
- stops making babbling sounds after having once started...
- has frequent ear aches or running ears...
- speaks always in very loud or very soft voice...
- tends to omit parts of words...

--TALKING

If Your Child...

- is not babbling by 6 months...
- does not respond to the spoken word by age 1...
- is not using single words by age 2...
- is not understood when talking by age 3...
- is not talking in short sentences by age 4...

--THINKING

If Your Child...

- does not react to his/her own name when called by age 1...
- is unable to identify hair, eyes, ears, nose and mouth by pointing to them by age 2...
- does not understand simple stories told or read by age 3...
- does not give reasonable answers to such questions as "What do you do when you are sleepy?" or "What do you do when you are hungry?" by age 4...
- does not seem to understand the meanings of the words "today", "tomorrow," "yesterday" by age 5...

THEN... consult your physician or an early intervention program (the Lake-McHenry Regional Program or the Low Incidence Cooperative Agreement, LICA, Program). In addition, some diagnostic clinics do take self-referrals. Check with the directory in the back.

Sometimes mentally retarded babies are described as being "perfect babies". They are often very quiet and content, and seem to sleep for long amounts of time during the day. They hardly ever cry. On the other hand, some mentally retarded babies are very restless and fretful. As parents you must be careful that the "quiet baby" is not being so "good" because of an inability to pay attention to all the things that are going on around. The restless baby may be aware of things, but may shift attention too quickly from one thing to the next, not being able to focus on any one event long enough to absorb it. Both babies need to have someone help them focus their attention towards one object at a time. One of the easiest ways of doing this is through play. Through play, the child's interests can be aroused, and attention can be drawn to specific sounds, objects or movements. Teach your child to become aware of his or her body. Play with the baby's toes, hands, and fingers. Play "Peek-a-boo" or "This little piggy went to market". Show your child each finger as you count them. Place small objects into your child's hands, exposing him or her to shape and texture. Teach your child how to use a finger to point to things. Introduce the world of sound by demonstrating all the different sounds that you can make. Make funny faces for your child, using his or her finger to point to the different parts of your face. Open up the world of movement by rocking your child in your arms, or gently rolling your child over, or move your child's hands and feet together. It is during these times of play that the most active learning goes on for the mentally retarded child. The degree to which your child will develop his or her potential depends largely on the love and support which you give.

Treatments

There is no cure for mental retardation. None of the underlying genetic, chromosomal, or neurological defects can be corrected. The aim of dietary, therapeutic and educational programs is to minimize the mental and physical disabilities. Parents of mentally retarded children may be unduly susceptible to claims of quacks, charlatans and well-meaning but mistaken people that a cure can be effected, or that a particular treatment will remarkably improve a child's development. Through the years a host of drugs and diets of various kinds have been promoted. Objective evidence as to the effectiveness of most of them is lacking. Two noteable exceptions are the special diet for children born with phenylketonuria (PKU) and the treatment for hypothyroidism which can prevent mental retardatinn from occuring -- they could not, of course, reverse the effects of mental retardation if it had already developed.

You should be aware that there are some important strains between experimental research and therapeutic or educational help. Good experimental research is conducted on narrow questions which can be answered (as to whether the treatment makes a difference or not) by available methods. Children ("subjects") are selected to fit the research design. Individual differences are minimized. Treatment obviously cannot be nearly so precise. Treatment must be prescribed for children who are unique individuals. Experimental treatments may not be effective for your child even though they do work for other children; on the other hand, unproven treatments may work for your child. You may be willing to try out some new treatments even though they are controversial. You should be open to the idea that your child could benefit from new discoveries or unproven treatments. At the same time, you have certain financial, physical and emotional limitations. If a treatment would require undue sacrifices from the family, then it is not for you. If you do try a new or unproven treatment you should do so with the idea that there is only a small probability that it will help your child. Be optimistic, but do not hold out unrealistic expectations.

One controversial treatment is "Freshcell Therapy" as practiced at Clinic La Prairie founded by Dr. Paul Niehans in Switzerland (Contact: Professor Niehans U. S. Information Center, New Life International, 1102 Grand Avenue, Suite 222, Kansas City, Missouri 64106, telephone (816) 842-8831). Cellular injections begun in early infancy are thought to reduce later retardation.

The intensive use of physical therapy and other treatments, as in the Doman-Delacatto method (discussed in the section on Cerebral Palsy), has had more success with children having physical impairments due to brain-damage than in the treatment of children whose primary disability is mental retardation--though Doman-Delacatto claims to help children of varying disabilities.

Another treatment, the Feingold diet, involves the strict adherence to an additives-free diet to lessen hyperactivity in children. Feingold claims that strict adherence to the diet should cure all children with hyperactivity, though research by others does not support his results.

You will undoubtedly come across many others. To verify the credibility of any new treatment, talk to your physician, the personnel at your child's school, and contact your local chapter or affiliate of the National Association for Retarded Citizens. They will be able to provide you with the most recent information about the treatments so that you may decide which ones may be beneficial for your child.

The outlook for a child with mental retardation depends on the level of the disability, your influence and support in the home, and obtaining an appropriate education (see Chapter on Education).

When considering educational alternatives for your child you should aim at choosing the level of special education which is least restrictive. Realistic expectations and goals should be set. Nothing will discourage a child faster than repeated failure because of over-estimated goals. In order for your child to become enthused with education and learning, he or she must experience the joy and pride of success. Although you will choose a program based on your child's present characteristics and needs, you should look for a program which advocates flexibility and integration of experiences with normal peers and others in the community. You will re-evaluate your child's progress periodically, and you may find that your child's needs have changed, making the current setting less suitable. At such a time, goals, expectations, and classroom settings may be ready for restructuring.

Recommended for Further Reading

Apgar, Virginia and Joan Beck. Is My Baby All Right?
1974 New York: Pocket Books.

A book for parents explaining birth defects and disorders occuring before or at the time of birth that are serious enough to require special medical care and/or educational help. Written in non-technical vocabulary, but does include a few medical words. NOT recommended as a book to read first because the book can seem uncomfortable, discouraging and frightening especially to those who are expecting or hope to have children in the future.

Buck, Pearl S. The Child Who Never Grew. New York: John Day.
1950

First appeared as an article for the general public in the Ladies' Home Journal. The author describes how she coped with the fact that she had a mentally retarded daughter. A very readable way of informing others about the feelings of a family with a retarded child.

Barnard, Kathryn E., and Marcene L. Erickson. Teaching Children with
1976 Developmental Problems: A Family Care Approach. St. Louis: C.V. Mosby.

Presents information, rationale, and the process used by the authors in working with disabled children in infancy and early preschool years who live with their families. Includes suggestions for parents, nurses and others who work with these children on how to assess and observe the children with techniques for teaching self-feeding, toileting, dressing skills.

Grossman, Herbert J. (ed.). Manual on the Terminology and Classification
1977 in Mental Retardation. Washington, D.C.: American Association on Mental Deficiency.

Quite technical. The A.A.M.D.'s attempt to provide a definition and classification system for use in the field of mental retardation. Contains definitions on all types of diseases and disorders and includes tables of expected adaptive behavior levels for all types of mental retardation.

Horrobin, J. Margaret, and John E. Rynders. To Give an Edge: A Guide for
1975 New Parents of Down's Syndrome (mongoloid) Children. Minneapolis: Colwell Press.

Presents both sides to the question of whether parents of Down's Syndrome children should keep their children at home or place them in foster homes or institutions. Presents facts about the syndrome and knowledge of how other parents of Down's children have coped.

Hunt, Nigel. *The World of Nigel Hunt: The Diary of a Mongoloid Youth.*
1967 New York: Garrett Publications.

An autobiographical essay written by a Down's Syndrome young adult. An interesting view of the world through the eyes of someone with a serious developmental disability.

Klein, Gerda. *The Blue Rose*. New York: Lawrence Hill.
1974

Wonderful, simple book which tells the story of Jenny, a young mentally retarded girl and what it is like to be different. For use with siblings and other children to help them understand what it is like to be mentally retarded. Good photographs to illustrate text.

Koch, Richard and Felix F. de la Cruz. *Down's Syndrome (Mongolism): Research, Prevention, and Management*. New York: Brunner/Mazel.
1975

Assesses developments in research, prevention, and management presented at a recent national conference. Presents authoritative findings on effects of new and controversial treatments. Focuses on prevention and diagnosis, the important function of early intervention programs, and the interaction of the mentally retarded individual with the larger world of work, family, friends, and society.

Macmillan, Donald L. *Mental Retardation in School and Society*. Boston: Little, Brown.
1977

Textbook emphasizing the importance of psychosocial and educational issues related to mental retardation, rather than the biological, medical, and genetic aspects. Topics include the effects of labeling children, testing minority children, mainstreaming, due process, diagnostic-prescriptive techniques, and the impact of mental retardation.

Perske, Robert. *New Direction for Parents of Persons Who Are Retarded*.
1973 Nashville: Abingdon.

Deals with attitudes of parents and family toward a family member with retardation. Challenges parents to work: at getting their own thinking straight about the mental retardation of their child; at seeing their child's human needs for joy, success and acceptance; at trying for the healthy reorganization of their family so that the retarded child can definitely be a part of it; and at organizing other parents in order to tackle society's long-standing and unfair prejudices against mentally retarded citizens. Beautiful line drawing illustrations.

Robinson, Nancy M., and Halbert B. Robinson. *The Mentally Retarded Child: A Psychological Approach*. New York: McGraw-Hill.
1976

A psychologically-oriented textbook concerned with mental retardation. The authors focus on the large, gray borderline between low-average human mental achievement and the deficiency of the severely retarded. They also discuss the historical and recent developments in special education of mentally retarded children.

Richmond, Julius B., George Tarjan, and Robert Mendelsohn (eds.). Mental
1965 Retardation: A Handbook for the Primary Physician. Chicago: American Medical Association.

Directed primarily toward practicing physicians. This handbook considers the problem of diagnosis and prevention, followed by detailed discussions of care and rehabilitation and the physician's involvement in continuing research and education. Recommend it to your child's pediatrician and other doctors.

For the latest information on recently published books and articles contact:

The National Association for Retarded Citizens
2709 Avenue E East
P.O. Box 6105
Arlington, Texas 76011

Parents' Campaign for Handicapped Children and Youth
Box 1492
Washington, D.C. 20013

Down's Syndrome Congress
118 Paloma Drive
San Antonio, Texas 78212

National Association For Down's Syndrome
282 West Fullerton
Addison, Illinois 60101

The U.S. Department of Health, Education, and Welfare through the Public Health Service and the Health Services Administration published A Reader's Guide for Parents of Children With Mental, Physical, or Emotional Disabilities by Coralie B. Moore and Kathryn Gorham Morton in 1976. It is for sale by the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C., 20402. Ask for DHEW Publication No. (HSA) 77-5290. Since there is always only a limited supply, this publication may be out-of-print. Ask the Superintendent of Documents to send you information on other publications.

Cerebral Palsy

Though the symptoms have been recognized and recorded throughout history, it was not until the end of World War II that Winthrop M. Phelps, a Baltimore doctor, became the first person to use the term cerebral (concerned with the brain) palsy (paralysis). Cerebral palsy is a general label used to describe central nervous system damage combined with many levels and kinds of muscle and sensory difficulties which give the disorder its distinctive pattern. Cerebral palsy is, realistically, a number of disorders.

A person with cerebral palsy usually has lifetime problems. Some of the effects -- inability to concentrate, emotional stress, perhaps seizure activity from time to time, to cite a few--may not appear at a glance. But, some of the clearly visible physical defects can be distressing. The consequences of jammed-up or overactive motor control centers of the brain make movements awkward, difficult, or altogether impossible. A walk may be more like a stagger. Arms wave involuntarily, sometimes wildly; speech stumbles, gags or halts. Or, perhaps, movements are stiff or impossible because of locked, spastic muscles. Sight, hearing, and other senses may be impaired, too. Of course, no one person with cerebral palsy will suffer from all these disabilities and the degree to which any symptom is present will vary.

Causes of Cerebral Palsy

Cerebral palsy usually occurs during pregnancy or the first few years of life when the brain develops. Scientists believe that the young brain is especially sensitive to interference with blood circulation or changes in blood chemistry. For example, interferences in brain activity and growth can be caused by a lack of oxygen (anoxia) to the brain, by infections or diseases, or by some kind of head trauma (injury or shock). There are many causes for cerebral palsy, yet seldom is it heredity. Anoxia, a lack of oxygen to the brain, is the leading cause, but no definite cause can be found in forty percent of the cases.

Cerebral palsy affects between one and five children per thousand under the age of twenty-one. In the six-county Chicago area, there are about 24,000 people with cerebral palsy.

Types of Cerebral Palsy

Classifications of cerebral palsy have been based on the character of the disordered movement, the various parts of the body afflicted, the degree of impairment, and the associated disabilities.

The most familiar classification is based on the character of the disordered movement. Three main types are identified: spastic, athetoid and ataxic.

Spasticity involves tense, contracted muscles. When a child with spastic cerebral palsy tries to move, the muscles counteract one another, making movement difficult or impossible. Spasticity affects 50-60 percent of those with cerebral palsy.

Athetosis is characterized by involuntary exaggerated movement of the arms, legs and head. Constant uncontrolled motion of the limbs and head, especially the fingers and wrists, is apparent except at rest or sleep. Athetosis affects 20-25 percent of those with cerebral palsy.

Ataxia refers to a lack of coordination due to a disturbance of balance. This poor sense of balance often causes stumbles and falls, making any kind of movement difficult. Ataxia affects 1-10 percent of those with cerebral palsy.

Children having various combinations of the above types of disordered movements account for 15-40 percent of the children with cerebral palsy.

The following table represents a classification of cerebral palsy according to the parts of the body affected:

1. Hemiplegia -- one side of the body (either right or left) is impaired -- 30-40 percent.
2. Diplegia -- the legs are more impaired than the arms -- 10-20 percent.
3. Quadriplegia -- all four limbs are impaired -- 15-20 percent.
4. Paraplegia -- the legs only are impaired -- 10-20 percent.
5. Monoplegia -- one limb is impaired -- rare.
6. Triplegia -- three limbs are impaired -- rare.

The degree of severity is part of the classification. Only finely precise movements, such as writing or talking are impaired in children with mild cerebral palsy. Moderate cerebral palsy impairs gross movements (such as walking where crutches or braces may be needed), fine movements or speech clarity; but the performance of usual activities is possible. Severe cerebral palsy involves the inability to perform adequately many of the usual daily activities such as walking, using hands, or using speech for communication.

Many classifications of cerebral palsy include the physical, intellectual and emotional problems that may be associated with the condition. Often vision, hearing and sight may be impaired. Convulsions may accompany the disorder. The children may have learning problems due to mental retardation or emotional and behavioral problems.

Detection

Early identification of cerebral palsy in babies can make it possible to provide treatment and training that can reduce the extent of the disability and prevent severe deformity. Unfortunately, cerebral palsy cannot be cured, but the earlier the treatment can be started, the easier it is for the child and the family to adjust to the disability.

Symptoms vary widely depending on the severity and location of the brain damage. Some children with cerebral palsy may show no obvious signs for a long time. Others may have serious symptoms from birth. Some physical symptoms evident at birth or in early childhood are difficulty in sucking, poor muscle control, poor coordination, problems with hearing and seeing, and muscle spasms and seizures. Some behavioral symptoms are unusual tenseness and irritability as an infant, and poor ability to concentrate.

These symptoms are not unique to children with cerebral palsy. If your child shows any of these symptoms, a thorough assessment should be undertaken to diagnose the nature of the cause (see this manual's section on Diagnosis and Assessment). For example, children with phenylketonuria (PKU) have the same marked irritability as do children with cerebral palsy. Treatment of PKU involves adherence to a strict diet to eliminate the irritability and other symptoms of the disability. Such a diet would probably be of no use to a child with cerebral palsy. Correct diagnosis is important for the treatment of cerebral palsy.

Treatments

There is no cure for cerebral palsy, but much can be done to help people with cerebral palsy become self-reliant. Mechanical aids, such as communication devices, special eyeglasses and hearing aids, walkers, braces, wheelchairs, and specially equipped cars can make life more normal. Medication can often relieve a person with cerebral palsy from seizures and muscle spasms. Surgery can help some specific problems, such as certain eye and ear difficulties and walking problems. Most useful are physical and occupational therapies. These therapies involve "motor re-education" exercises that help children to gain better control of their limbs. When combined with mechanical aids, therapy can help children have better mobility. Speech therapy helps cerebral palsied children acquire better communication skills, which allows for better social, education, and vocational opportunities. Counseling, either individual or group, helps those with cerebral palsy deal with emotional, social, and practical problems related to their physical handicaps. Treatment is tailored to the individual. Since cerebral palsy is not a single condition, there is no one single treatment for it.

The outlook for a person with cerebral palsy depends on the extent of the disability. Many will be able to attend public schools in special education or regular attendance classrooms. Some will need residential care because of their severe physical complications. About one-third of the people with cerebral palsy test at normal or above normal on intelligence tests and may be able to attend college. Whatever the extent of the disability, each cerebral palsied person is entitled to gain every bit of independence possible. Realistic vocational guidance should be a part of schooling programs for the cerebral palsied to prepare them for jobs which are within their abilities.

Families can help their cerebral palsied children to adjust to their disabilities and make the best of their lives. For parents of cerebral palsied children under six years of age, the book, Handling the Young Cerebral Palsied Child by Nancie R. Finnie, shows how parents, as the most important part of the team educating the child, can be partners with therapists and educators. How to Create Interiors for the Disabled by Jane R. Cary, is a guidebook showing parents how to adapt their home environments to the abilities of their handicapped children. For those with cerebral palsy who have average or above average intelligence, Sol Gordon's Living Fully: A Guide for Young People with a Handicap, Their Parents, Their Teachers, and Professionals, will help the cerebral palsied manage home and school daily activities. Sara Bonnett Stein's About Handicaps helps explain cerebral palsy to brothers, sisters, and other children. Karen and its sequel With Love From Karen are Marie Killilea's autobiographical accounts of her cerebral palsied daughter's struggle for independence through education in mobility and reading and writing.

Research is being conducted to try to eliminate the causes of cerebral palsy and also to try to find cures or better treatment for those who do have cerebral palsy. (The manual's section entitled "More Children" discusses the best ways known to prevent disabilities from occuring.)

There is much controversy over a treatment known as the Doman-Delacatto method. It is used at the Institutes for the Achievement of Human Potential in Philadelphia and elsewhere around the world. Dr. Glenn Doman has developed techniques to treat brain-injured children and has reported some great successes, but the treatment plan has drawn much criticism from other medical researchers. The techniques and the history of the Institutes are discussed in Doman's book, What To Do About Your Brain-Injured Child. Opposing viewpoints can be found in issues of the magazine Exceptional Children since 1966. The latest information on current research, and more information on self-help is available from the United Cerebral Palsy Association of Greater Chicago, 343 South Dearborn Street, Chicago, Illinois 60604, telephone 922-2238; or the United Cerebral Palsy Associations, Inc., 66 East 34th Street, New York, New York 10016.

Recommended for Further Reading

Cary, Jane Randolph. How to Create Interiors for the Disabled. New York
1978 Pantheon Books.
A guidebook for families and friends of the disabled for the construction of home environments that are useful and comfortable for the disabled.

Doman, Glenn. What to Do About Your Brain-Injured Child or Your Brain-Damaged, Mentally Retarded, Mentally Deficient, Cerebral-palsied, Emotionally Disturbed, Spastic, Flaccid, Rigid, Epiliptic, Autistic, Athetoid, Hyperactive Child. Garden City, New York: Doubleday.
1974

Documents the history of the Institutes for the Achievement of Human Potential which the author helped start and the techniques and treatments used at the Institutes to try to help cure the disabilities of children mentioned in the title. Since this treatment is quite controversial, parents should investigate thoroughly before accepting this book at face value.

Finnie, Nancie R. Handling the Young Cerebral Palsied Child. New York: E. P. Dutton.
1975

Recommended by United Cerebral Palsy as the best guide for parents, nurses, therapists, doctors, social workers, and others involved in the caring for young children with cerebral palsy. Teaches techniques for sleeping, toilet training, bathing, dressing, feeding, and other daily activities that can be done at home. Includes a checklist to assess the abilities of a cerebral palsied child.

Gordon, Sol. Living Fully: A Guide for Young People with a Handicap, Their Parents, Their Teachers, and Professionals. New York: John Day.
1975

Designed to enhance the self-acceptance of youths with handicaps who are of at least potentially average intelligence, and who are, for the most part, able to take care of themselves. Focuses on everyday problems of home and school "management," concentrating on basic socialization needs which will enhance opportunities for adult happiness.

Killilea, Marie. Karen. New York: Dell.
1960

A case study of one mother's experience with a cerebral palsied child, from birth in 1940 through her first eleven years. Documents the economic, social, and emotional hardships and rewards involved in educating Karen to be mobile, read and write, as well as the early growth of United Cerebral Palsy Association. Somewhat outdated although its easy readabily still makes it a good book for background information on cerebral palsy. Recommended for high school students and the general public.

Killilea, Marie. With Love From Karen. New York: Dell.
1964

Sequel to Karen. Continues through her 21st year.

Stein, Sara Bonnett. About Handicaps: An Open Family Book for Parents and Children Together. New York: Walker.
1974

Explores the relationship between two children, one of whom is handicapped. Has separate texts for the adult and child--vivid photographs and simple language make it easy reading for a child, while parents and teachers can follow an accompanying text that provides more specific details.

Epilepsy

The brain has millions of nerve cells, called neurons, which work together to control or guide whatever we do. To do their work, the nerve cells build up a supply of electricity through the action of chemicals they contain. Each cell has its own storage battery, which discharges electricity at the proper moment and then recharges immediately.

But cells, through injury or disease, can become overactive and fire off irregularly. This disturbance can suddenly spread to neighboring areas or jump to distant ones or even overwhelm the brain when it spreads.

When this happens, a seizure results. Persons who are identified through medical tests as having had one or several seizures are said to have epilepsy.

Anyone at any time can experience injury or disease that can lead to epilepsy. It is estimated that there are about 2,000,000 Americans with epilepsy, and 100,000 new cases develop each year. When properly understood and medically supervised, epilepsy should not prevent most people from leading a full, productive life. At least fifty percent of all cases of epilepsy can be controlled with proper medication; about thirty percent can gain partial control; and twenty percent usually have an additional disability that makes treatment difficult.

In the past it was widely believed that epilepsy was inherited. But as more specific causes were discovered, researchers began to believe that epilepsy was not inherited at all.

Researchers do believe that children can inherit greater susceptibility to seizures, but not epilepsy itself. Anyone can have a seizure if the brain is sufficiently irritated. Persons having a low threshold to seizures will develop seizure activity with less stimulation than others with higher thresholds. Almost everyone knows of some past or present relative who has had seizure activity. Parents and potential parents should not worry about passing on a tendency for epilepsy, unless their family history shows a strong recurring pattern of persons having epilepsy. (See section on "More Children" which discusses genetic counseling.)

Causes of Epilepsy

Seizures can be caused by head injuries (at birth or after), scars in brain tissue, malformations and certain chemical disorders. Sometimes the cause is unknown. Some of the more common causes that may be preventable follow.

Lead poisoning is one cause of seizure activity that can be prevented. Lead poisoning usually results from eating paint chips or dust that contains small amounts of lead. Before 1950, most houses were painted with paint containing excessive amounts of lead. Homes in deteriorating condition are particularly susceptible because of peeling paint. Close to fifty percent of the children between the ages of one and three have urges to eat nonfood items like paint, dirt, and dust. At times, these children may put into their mouths everything in sight. Lead poisoning by ingestion of paint chips is a major cause of epilepsy. Another source of lead poisoning is pottery made with lead glazes. When high acid foods like orange juice or colas are put in these kinds of containers, the lead mixes with the drink and is consumed. Exposure to all known sources of lead should be decreased to help prevent lead poisoning.

More causes of seizures are the common childhood diseases of measles, mumps, and diphtheria. These can be prevented by making sure that children are given immunizations on schedule. (See section on "More Children" for the immunization schedule.)

Head injury, due to accidents, accounts for a large number of children who have epilepsy. The most frequent causes of epilepsy in children are car accidents and falls on hard pavements.

Some other causes are nutritional deficiencies, high fever, brain tumors, and abscesses (a localized collection of pus in any part of the body, formed by tissue disintegration and surrounded by an inflamed area). Any one of these factors, when followed by seizure activity, has caused some injury to nerve cells in the brain, or to the way the nerve cells interact with one another.

When the cause of epilepsy is found the disease is called "symptomatic" epilepsy. When the cause cannot be found, the disorder is termed "essential" or "idiopathic" epilepsy.

Types of Epilepsy

Epilepsy is usually classified by the type of seizure that a person has. Seizures used to be described as grand mal, petit mal, and psychomotor. There is a new classification system which divides seizures into two main groups, partial and generalized.

The partial seizure affects only part of the brain. One example of a partial seizure is a psychomotor seizure. This might involve complex visual and auditory hallucinations, a dream-like state, and automatic movements in which the individual continues to perform some act over and over, for example, chewing and lip-smacking.

Generalized seizures are those which appear to affect the whole brain at once. There is a loss of consciousness and the whole body is affected from the onset. There are two main kinds.

One form of a generalized seizure is the petit mal, or absence seizure. Suddenly and without warning a person stops an activity and enters a momentary trance. The attack usually ends quickly and the person carries on as if nothing had happened. Sometimes rhythmic blinking or random, jerking motions occur Other times there is a sharp increase in muscle contraction, or a reduction of muscle tone. To the observer it may appear that the person is daydreaming or staring at nothing. This kind of seizure may strike as often as one hundred times a day, lasting only a few seconds each time.

The second form is grand mal seizure. While some experience a vague and ill-defined warning, known as an aura, most lose consciousness without knowing that a seizure is about to happen. A sudden, sharp, rigid contraction of the muscles is often accompanied by irregular breathing and drooling. When the convulsion is over, there is relaxation of the muscles, and the person may fall asleep.

Detection

Electroencephalograms (EEGs) are the best means for detecting epilepsy. It is a simple, non-invasive process done in hospitals and clinics on an outpatient basis. The whole procedure takes only a few hours, at most.

In preparation for the EEG, a technician may give the person a relaxing liquid to drink. Then the technician parts the person's hair in several places and pastes tiny flat discs, called electrodes, on the scalp. Each disc picks up an electric current from a different part of the brain. A wire carries each brain current to a device that looks like a radio receiver, where the tiny current is amplified. Each amplified current moves a pen that is held against a moving band of paper. The record of the EEG is a series of long wavy lines--one for each section of the brain where the discs are placed.

The technician can analyze the band of paper and determine if the person has brain waves that indicate epilepsy. The process if not foolproof, but it is accurate with ninety percent of the cases.

As complex as the EEG is, only brain waves can be detected. The EEG in no way can measure thoughts, intelligence, or mental health.

Another means of detecting epilepsy is the Computerized Axial Tomographic (CAT) Scan, a type of computer and x-ray combined. A CAT Scan takes pictures of the organ from many sides which the computer combines into a three-dimensional picture. This process analyzes the whole organ at once. Brain tumors can be pinpointed this way. This method is quite expensive and is only used when other tests indicate a possibility of visible brain damage.

There are other tests which can be used to detect brain damage as a possible cause for epilepsy. They involve injections that are potentially harmful to the patient. EEGs and CAT Scans are the safest and most effective diagnoses so far.

Treatments

Chemotherapy, or drug therapy, is now the most common treatment for epilepsy. Anti-epileptic drugs stop seizures from happening. How they change the seizure threshold or how they prevent the electrical seizure discharge from happening is not fully known. It is not known why some drugs are effective against seizures while others, which are much the same chemically, are not.

Many anti-convulsant drugs are available by prescription. Purchasing drugs through the Epilepsy Foundation of America's Prescription Drug Program (see directory) or by asking your pharmacist to fill the prescription with the generic name of the drug can save money for the person with epilepsy.

Here is a list of antiepileptic drugs by their trade and generic names:

TRADE	GENERIC
Atabrine	Quinacrine
Celontine	Methsuxmide
Clonopin*	Clonazepam
Depakene	Valproic Acid*
Dexedrine, Benzedrine	Amphetamine
Diamox	Acetazolamide
Dilantin	Phenytoin Sodium
Gemonil	Metharbital
Leminal, Stental, Eskabarb	Phenobarbital
Mebaral	Mephobarbital
Mesantoin	Mephenytoin
Milantin	Phensuxmide
Mysoline	Primidone
Paradione	Paramethadione
Peganone	Etthotoin
Phenufone	Phenacemide
Tegretol*	Carbamazepine
Tridione	Trimethadione
Valium	Diazepam
Zarontin	Ethosuxmide

*Tegretol, Clonopin and Valproic Acid were introduced and approved in this country in 1974, 1975, and 1978, respectively.

One of the latest breakthroughs in drug therapy is not a drug at all, but a laboratory technique in which a sample of blood is taken from the person and chemically analyzed to measure the amount of anticonvulsant drugs in the bloodstream. By monitoring how much of the drug is in the bloodstream the doctor can see if the dosage is too low to be effective or so high that it could cause unpleasant and dangerous side effects. If a person is taking several kinds of drugs and is having some problems, the blood level testing will show which drug is causing the problem. In earlier days, the doctors had to test by trial and error. With blood level testing, it is much simpler to prescribe dosages that will give maximum seizure control with minimum side effects.

There are a few cases of epilepsy where other methods are used. Some cases may need surgery; with others, special diets can work.

There are a very limited number of patients for whom surgery is appropriate. Surgery is only done when seizures cannot be controlled by drugs or the person has partial epilepsy arising from a part of the brain which can be removed without causing significant physical and intellectual loss.

Another kind of treatment is the Ketogenic diet which consists of foods with high fat content and low carbohydrates (for example bread and cereal). A palatable version of the diet involves a special oil, MCT oil, that is used in cooking and mixed with the foods to get the proper amounts of fats. The diet must be supervised by a physician.

New experimental procedures include acupuncture and biofeedback. Acupuncture is an Oriental method of treating illnesses by inserting needles into various parts of the body. Biofeedback involves training persons with epilepsy to control the rhythm of their brain waves in order to avoid seizures.

Because of the research already completed, treatments of epilepsy have advanced farther in the last 25 years than during the preceeding 25 centuries. By knowing more about the nature of epilepsy and how anti-epileptic drugs work, research may lead to even more effective treatments of epilepsy.

For more information on epilepsy contact the Epilepsy Foundation of American (EFA). The EFA has pamphlets and lists of books to order.

Autism

Autism is a severly incapacitating life-long developmental disability. To differentiate it from some of the disintegrative psychoses which begin about age three, the World Health Organization takes 30 months as its cut-off point for the onset of autism. It occurs in approximately five out of every 10,000 births and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic, and social backgrounds. One of the most interesting historical documents describing a child with autistic behaviors is The Wild Boy of Aveyron by J.M.G. Itard first published in 1799. The educational methods Itard developed are still influencing the teaching of handicapped children today.

Though the symptoms had been recognized and recorded earlier, it was not until 1943 that Leo Kanner used the term to describe a set of puzzling, bizarre and inappropriate behaviors observed in children with disturbed behavior. These features included an inability to develop relationships with people, a delay in speech acquisition, the noncommunicative use of speech after it develops, delayed echolalia, pronominal reversal, repetitive and stereotyped play activities, an obsessive insistence on the maintenance of sameness, a lack of imagination, a good rote memory, and a normal physical appearance. Autistic children seem at first to be strikingly different from normal children and from children with more common childhood disabilities. However, each of the problems they show can be found in other handicapping conditions and can often be observed in normal children at different developmental stages as well. Autism is more than a simple label; it describes a tendency towards a particular grouping of behaviors. Of course, no one child with autism will exhibit all of these disturbed behaviors and the degree to which any symptom is present will vary.

Causes of Autism

Originally, Leo Kanner had thought that autistic children were really of normal intelligence and that their poor functioning was due to their failure to make social relationships. Subsequent IQ testing, however, has shown approximately 60 percent of children with autism have scores below 50, 20 percent between 50 and 70, and only 20 percent greater than 70 (see chart on "Levels of Mental Retardation" in that chapter). In short, autism and mental retardation frequently coexist. Most autistic children show wide variations of performance on different tests and at different times.

The choice of the term "autism" led to some unfortunate confusion initially, because this term was also used to refer to the active withdrawal into fantasy characteristic of schizophrenia. That is, autism -- a developmental disability characterized by a failure to develop social relationships -- was confused with certain types of mental illness in which there is a withdrawal from relationships. This confusion is illustrated in Bruno Bettelheim's research monograph entitled The Empty Fortress: Infantile Autism and the Birth of the Self. Unfortunately, Bettelheim's confusion between mental illness and developmental disabilities has been transmitted to many professionals and parents in Illinois and elsewhere through his work at the Orthogenic School at the University of Chicago. Bettelheim theorized, from a psychoanalytic point of view, that autistic children "chose" to withdraw from relationships because of interpersonal problems evidenced by their parents, especially their mothers (sometimes caricaturized as "refrigerator parents"). A large number of studies "blaming" parents for childhood autism were published in a short period of time, particularly before 1965. As parents you should be extremely skeptical of such literature and of professionals who indicate they have been influenced by such views in the questions they ask. It is true that autistic children may cause parents to act differently than they do with normal children -- parents of children with autism use shorter sentences, more questions, more commands, and more rewards and punishments for example -- but this would be true for any adults interacting with children who have other kinds of communicative disorders as well. In short, adults' interactions with children, including parents' interactions with autistic children, may be affected by the verbal and behavioral skills (or lack of skills) of the children. Careful examination of all the research evidence gives no support to the theory that certain family characteristics are necessary causes of autism.

During the late 1950's and early 1960's, Bernard Rimland and others challenged the confusion between autism and mental illness, clearly identifying autism as a developmental disability. In his book, Infantile Autism, Rimland explains his theory. Autism could be caused by injury or infection, or could be congenital. Research so far has not determined any one cause for autism, but perhaps the most promising leads are in the areas of biochemical and neurophysiological research.

There is evidence to support the theory that the problem lies in the parts of the brain that deal with the organization of information coming in from all the senses (sight, smell, hearing, taste and touch), and in the perception and integration of sensory input. A number of different disabilities combined result in a severe communication problem. Each disability, by itself, will affect some aspect of the child's ability to communicate meaningfully with other people, and will lead to some social and behavioral difficulties. The behavioral problems are multiplied and affect every aspect of life. This is what happens in autism.

At the time of publication of this handbook, one of the most up-to-date reviews of current knowledge about causation is Michael Rutter and Eric Schopler's Autism: A Reappraisal of Concepts and Treatment, based on papers presented at the 1976 International Symposium on Autism. The National Society for Autistic Children publishes a continually updated comprehensive list of publications available through their bookstore including proceedings from their annual meetings.

Symptoms of Autism

In his earliest (1943) description of autistic children, Kanner provided lengthy clinical histories on eleven children. He did not present the symptoms in any logical framework and it was difficult to sort out the pattern well enough to match individual children with it. Also, children's behavior changes with age and with mental development (IQ), making the problem of matching children to his description even more difficult. It is not surprising that later researchers preferred to use briefer summaries and that they tried to distinguish between those behaviors which were specifically characteristic of autism and those behaviors which could occur in some autistic children but not in all. There are a group of children who exhibit some aspects of autism and a much smaller number who show all of the symptoms described by Kanner. Different researchers selected different samples of children of different ages, all of whom had some symptoms in common but some different symptoms too. This affected their opinions on the relative importance of different behaviors. It is necessary to evaluate the literature about "autism" very carefully to determine what types of children are being studied. The label has been applied differently although there is a current movement towards agreement.

Early childhood autism is defined in terms of an abnormal behavior pattern. There are no objective tests upon which to base a diagnosis. The best procedure at the present seems to be to define autism in terms of four essential criteria in relation to the child's behavior before age five. The four criteria are:

(1) an onset before the age of 30 months;

(2) impaired social development which is out of keeping with the child's intellectual level and which has a number of special characteristics -- a lack of attachment and a relative failure of bonding (for example, physically stiffening and rejecting cuddling, or not following, greeting, or going to their parents), a failure to use eye-to-eye gaze in a normal fashion (for example, not looking at people's faces to gain their attention, to be picked up, when being aggressive towards them, or when being spoken to);

(3) delayed and deviant language development which also is out of keeping with the child's intellectual level and has certain defined features --

- in prelanguage skills -- failure to show much social imitation such as waving "bye-bye", delay in the meaningful use of objects such as spinning the wheels of a car ritualistically rather than rolling the car in the intended way, and lack of imitative or make-believe play such as entering into imaginative and ever-changing pretend play.

- in language skills -- impaired or abnormal patterns of babble towards the end of the second year, impaired understanding of the spoken language such as only following simple instructions in a familiar setting or with the aid of a gesture;

(4) "insistence on sameness" as shown by stereotyped play patterns, abnormal preoccupations, or resistance to change -- for example, they may --

- persevere in rhythmic body movements including swaying, rocking, twirling, head banging, jabbing with their fingers into their heads, fluttering their hands, writhing and squirming;
- develop a strong attachment to one thing (a piece of string, a dish rag, or some other object) which they manipulate ritualistically for months or even years;
- adjust with great difficulty to changes in their daily routine (for example, they become extremely upset when a certain object is out of its regular place, or when they do not go to school on a regular school day due to a bad snowstorm).

More than half of autistic children, especially those who are also mentally retarded, never gain useful speech. Among those who do learn to speak there are a variety of characteristic abnormalities such as echoing what someone has just said (echolalia), an I-You pronominal reversal (saying "You want a cookie" meaning "I want a cookie"), the delayed repetition of stereotyped phrases, and a tendency not to use speech in the usual way for social communication (for example, responding with something that does not seem related to what they have heard).

These behaviors are occasionally exhibited by most children during their first three years. What is different is that the autistic child will exhibit more of these symptoms, more often, and in a repetitious and monotonous fashion. For a more detailed description of the behaviors of autistic children, read Lorna Wing's guide for parents and professionals, Autistic Children; and Rutter and Schopler's Autism.

Detection of Autism

Determining whether a child has autism is not an easy process. Generally parents are aware that there is something different about their child, but have little success in finding anyone with sufficient expertise to make a differential diagnosis. Of all the disabilities, this is one which takes the most tremendous toll on parents, both because they are living with an extremely aberrant child and because there is so little support or understanding of them as they try to cope with a catastrophic illness. The autistic child looks normal and is frequently unusually attractive. This compounds the problem as the general public ascribes the inappropriate and difficult behavior to poor parenting. Professional persons across disciplines rarely recognize the need for a complete diagnostic evaluation, nor, if they recognize the need, do they know where to refer the family for help.

Due to the small number of autistic cases (about three to five per ten thousand children), testing for autism is usually done in a specialized clinic at a large hospital diagnostic center. The doctor will ask the parents for a complete history of the child's behavior in as much detail as possible, from birth up to the time of the exam. The decision about whether a child has autism or not depends upon the presence or absence of special patterns of behavior, like those discussed earlier. Different checklists, composed of questions about the child's abilities and disabilities, have been devised to help doctors decide if a child has autism. Since there is no known cause nor any proven cure, several different overlapping checklists have been invented by different professionals espousing different theories of the causes of autism.

Diagnosis does not take place by simply checking off a certain number of behaviors on a checklist. Since the behaviors exhibited by autistic children can also be associated with other childhood diseases and handicaps, medical tests and evaluations are performed to determine if there are any known medical causes for the child's behavior. Due to the mystery of the causes of autism and the many different theories of its cause, parents of a child who seems to be exhibiting autistic-like behaviors could get a different diagnosis from every clinic where they have their child tested.

Children are more frequently mis-diagnosed than correctly diagnosed. Because of the difficulties of assessment, a reliable evaluation requires an extended period of time and should include, at a minimum, medical, psychosocial, audiotory, speech, psychological, and neurological evaluations. During 1978-79 the Illinois Society for Autistic Children was funded through the Illinois Office of Education and the Governor's Planning Council on Developmental Disabilities to develop a comprehensive model system for the delivery of services specific to the autistic population. Hopefully that study will result in a substantial increase in the levels of professional expertise and development of diagnostic resources throughout the state. Right now, a parent has to have tremendous energy and perseverance to secure an accurate diagnosis and to pursue appropriate programming.

Treatment of Autism

Most successful programs involve the parents and the whole family in the education and treatment of the autistic child. The programs usually consist of an educational program provided either in a school or at a special clinic of a hospital, and a home program where the parents at home or in the clinic are trained in how to manage their child's behavior. Edward Ritvo's Autism, and Martin A. Kozloff's Reaching the Autistic Child describe some worthwhile programs in which parents play a significant role. As discussed in the same section in the Chapter on Mental Retardation, extravagant claims for success should be regarded with suspect. As a parent you should be aware that these claims are usually based on highly selected small groups under experimental conditions. The claims may not be realized for your particular child.

A diagnosis of autism will be accompanied by written evaluations, usually including referrals to an educational program in the family's school district. Since there are very few programs explicitly designed for autistic children, referrals are made to many different special education programs depending on the child's abilities and disabilities and the programs offered by the school district. In the absence of special programs, autistic children are sometimes placed in classes for the behaviorally disturbed, classes for the mentally retarded, or classes for the learning disabled. You should inspect the program that your child may be placed in to see if the therapy and education being given by the program is consistent with what you and the diagnosing professionals think would be most helpful to your child. The programs should include lots of repetition and the teachers and therapists should use a lot of emotional expression.

The outlook for the development of children with autism is hopeful, but guarded. Autistic children require professional care for many years and, for most, throughout their lives.

Currently treatment is symptom reduction with behavior modification a significant tool. In general, medication is not too useful a tool, nor is psychotherapy. Psychotherapy can be useful to the child who is high functioning and needs to work out other emotional problems (see Chapter on Family Counseling). Certainly the partnership of parents and school staff is vital. For many children, maturation diminishes some of the problem behaviors. Occupational therapy, recreational therapy, communications therapy, music therapy, and adaptive physical education as well as a specialized academic curriculum are components of a necessary school-age curriculum. Special recreation and respite care can benefit the entire family (see Section on Family Support). The earlier vocational training is begun, the better, and certainly pre-vocational and vocational training are essential in the adolescent and young adult years.

Recommended for Further Reading

Bettelheim, Bruno. The Empty Fortress: Infantile Autism and the Birth of
1967 the Self. New York: The Free Press.
While this book is widely available in Illinois bookstores, parents should be aware that Bettelheim confused mental illness and autism and therefore describes children's behaviors, family characteristics, and therapeutic treatments which today would generally not be considered accurate. The work is interesting as an historical document about how much our understanding has progressed since it was written, and it could provide some useful insights, but it is not particularly recommended.

Copeland, James. For the Love of Ann. New York: Ballantine.
1973
Based on a father's diary, this is an account of an autistic girl, the problems she faces as well as those her parents must confront. The book presents the difficulties of autism in a hopeful light, and shows how one child overcomes her handicap.

Gold, Phyllis. Please Don't Say Hello. New York: Human Sciences Press.
1976
Written by the mother of an autistic child to explain the behaviors characteristic of autism to other young children. It explores the experiences of a family who move into a new neighborhood with their autistic son and the reactions of playmates and neighbors. Good photographs illustrate text.

Greenfeld, Josh. A Child Called Noah: A Family Journey. New York:
1970 Warner.
Written by a father, in the form of a daily diary, about the fifth year of life of his autistic son. Illustrates the difficulties of obtaining a reliable evaluation and appropriate placement.

Itard, Jean-Marc-Gaspard. The Wild Boy of Aveyron. Englewood Cliffs,
1962 New Jersey: Prentice-Hall.
Translated from the account of this French physician's work with a so-called "wild boy" captured in a woods by three sportsmen in 1799. Contrary to the thinking of that time, Itard felt the child was not "an incurable idiot" but lacked social skills because he had not had the opportunity to interact with other human beings. The educational philosophies which guided his treatment were the beginnings of special education as we know it today.

Kozloff, Martin A. Reaching the Autistic Child: A Parent Training Program.
1973 Champaign, Illinois: Research Press.
A parent-training manual detailing procedures for producing social and behavioral changes in autistic children and their families. The parents are the teachers. They learn how to teach their children to speak, play, and perform chores cooperatively.

Oppenheim, Rosalind. C. Effective Teaching Methods for Autistic Children.
1974 Springfield, Illinois: Charles C. Thomas.
Various teaching methods and techniques that the author, who directs the Rimland School for Autistic Children in Evanston, Illinois, developed during her first thirteen years of teaching and working with autistic children.

Park, Clara Claiborne. The Seige: The First Eight Years of an Autistic Child.
1967 Boston, Massachusetts: Little, Brown.
A mother's account of her autistic child and the family's way of coping and caring for the child.

Pieper, Elizabeth. Sticks and Stones: The Story of Loving a Child.
1978 Syracuse, New York: Human Policy Press.
A mother's story about persistence in the face of prejudice and discrimination from family, friends, and professionals. Describes how she learned to advocate for her child, for all the developmentally disabled, and for all people.

Rimland, Bernard. Infantile Autism: The Syndrome and Its Implications for
1964 A Neural Theory of Behavior. Englewood Cliffs, New Jersey: Prentice-Hall.
Presents an overview of knowledge about autism and considers several implications for autism caused by physical abnormalities in the brain.

Ritvo, Edward R. (editor). Autism: Diagnosis, Current Research and
1976 Management. New York: Spectrum.

Offers an overview of the medical aspects of autism and describes how the diagnosis is established. A section describes unique programs at two institutes. The role of parents as paraprofessionals is discussed.

Rutter, Michael and Eric Schopler (Eds.). Autism: A Reappraisal of Concepts
1978 and Treatment. New York: Plenum.

Quite technical. Provides an introduction to the definition and diagnosis of autism. Contributing researchers examine the social and familial characteristics of autistic children; psychological, genetic, and biological research findings; psychotherapy; biological and behavioral approaches to treatment; the education of autistic children; and long-term follow-up studies.

Wing, Lorna. Autistic Children: A Guide for Parents and Professionals.
1973 Secaucus, New Jersey: Citadel.

Shows how an autistic child views his fantasy world and explains his difficulties in perceiving and understanding events around him. Reviews the behavioral and emotional problems which must be expected and how these may be handled. Discusses particular stresses on family, services that can help, the role of parents' organizations, and the outlook for the future.

For more information and book lists on autism contact the National Society for Autistic Children, under that listing in the back of this manual.

A Noncategorical Definition of Developmental Disabilities

For as long as people have noticed differences, talked about them and written about them, labels for categorizing others have existed. When the labels obtain services -- "mental retardation," "cerebral palsy," "epilepsy," "autism" -- such categorical definitions have the power to help you and your child. You want the protection and services that the labels provide. But there are generally stereotypes which are associated with the labels -- "moron," "dummy," "crazy." These stereotypes have the power to hurt you and your child. You would like the hope for a better future implied by getting rid of the labels and stereotypes. However, even if eliminated, the differences remain. There need to be some criteria for obtaining special services. This is precisely the dilemma that is facing parents and professionals today.

In 1977 a National Task Force presented recommendations on the definition of developmental disabilities to the federal government. They proposed a noncategorical definition (that is, no labels) as follows:

> For purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:
>
> 1) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> 2) is manifest before age 22;
>
> 3) is likely to continue indefinitely;
>
> 4) results in substantial functional limitations in three or more of the following areas of major life activity:
>
>   a) self-care,
>   b) receptive and expressive language,
>   c) learning,
>   d) mobility,
>   e) self-direction,
>   f) capacity for independent living, or
>   g) economic self-sufficiency; and
>
> 5) reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are
>
>   a) of lifelong or extended duration and
>   b) individually planned and coordinated.

A disability is defined as "a form of inability or limitation in performing roles and tasks expected of an individual within a social environment." Further, the definition refers to "impairments" rather than specific categories of conditions. Under this definition a person who is mentally retarded, autistic, or who has epilepsy, or cerebral palsy, would no longer automatically be included under legislation and programs for the developmentally disabled. An individual would have to meet all of the other criteria specified in the definition as well to become eligible for services. Determining whether an individual is "substantially functionally limited" in three or more of the task areas identified would have to be established by testing against national norms or averages (as is currently the case for IQ tests) or by informed observation.

The purpose of the noncategorical definition was to include all the categories currently defined as developmental disabilities -- mental retardation, cerebral palsy, epilepsy, autism -- and to add other individuals with similar characteristics, for example, childhood psychosis (a mental illness) and quadriplegia (a physical impairment). But the intent of the noncategorical definition was to include only the most severely handicapped in any category. Whether more or less individuals would actually receive services is therefore quite ambiguous.

Out of the 47-member National Task Force, a significant number -- 12 members (approximately 25 percent) including the representative from Illinois -- were sufficiently concerned about the ambiguity of the noncategorical definition that they made a formal protest in the form of a Minority Report. Instead of the vague word "impairment" they recommended categorical disabilities also be named. They preferred that the wording combine features of both categorical and noncategorical definitions. The definition recommended by the Minority Report would read:

> For purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:
>
> 1) is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or is attributable to any other condition of a person similar to mental retardation, cerebral palsy, epilepsy, or autism because such condition results in similar impairment of general intellectual functioning or adaptive behavior and requires treatment and services similar to those required for such persons;
>
> 2 - 5) same as National Task Force definition.

The 12 persons signing the Minority Report do not believe programs and services for the developmentally disabled can be successfully administered without identifiable categories of disability. Endless interpretation of who is or is not developmentally disabled increases the potential for more testing, more paperwork and bureaucratic red tape, escalating costs, and exclusion of individuals in need of services. It is not clear what will happen in Illinois. No matter what definition is used, you and other parents will have to be very alert. Children should not be denied needed services due to the administrative requirements of legal and professional definitions.

Philosophy and History

The current attitudes about developmental disabilities are reflected in a variety of areas. The growth of interest in mainstreaming, or normalization, the decline of institutionalization, the amount and types of federal and state funding, the growth of voluntary associations, the rise of civil rights advocacy, and the type and availability of special facilities and programs, are all concrete examples of current philosophies about the nature of developmental disabilities. Efforts taken in any of these areas affects the whole situation. For example, a voluntary parents' group may lobby for the passage of a law to provide research grants to universities. These grants, in turn, may stimulate further services, publicity and involvement on a variety of levels.

Attitudes about developmental disabilities have not always been so positive. More than thirty years ago, philosophies were much different. Earlier beliefs that developmental disabilities were hereditary, unchangeable, and socially harmful created a demand for institutions where handicapped persons would be kept apart from the "normal" population. The original functions of institutions, teaching and training were all but forgotten. During the first half of the twentieth century, resident populations grew larger and larger, staff-patient ratios worsened, and residents were forced to work to help support institutional costs.

As early as 1925, basic premises about the nature of developmental disabilities began to change. However, it was not until the late 1940's and early 1950's, in an era of prosperity and social reform, that interest in the concerns of the developmentally disabled became widespread nationally and has grown since.

Parents' organizations started across the country in the 1940's as parents found that organizing into groups fostered better understanding of the problems of the developmentally disabled and created opportunities for their children. The tremendous growth of these parents' organizations has had a significant influence on the growth of services to the developmentally disabled. For example, The National Association of Parents and Friends of Mentally Retarded Children was founded in 1950 with 44 delegates representing 23 organizations in 13 states. The name of the Association was shortened in 1951 to the National Association for Retarded Children and changed in 1973 to the National Association for Retarded Citizens. By 1975 the membership of the organization exceeded 218,000 in over 1700 state and local units around the country. Other organizations for the developmentally disabled have shown similar growth patterns.

Due to the untiring efforts of parents to secure basic rights for the developmentally disabled, normalization or mainstreaming (the movement to provide education and training in the least restrictive, most stimulating environment possible) has become a national goal. In the 1970's and 1980's community-based services are desired. Towards this end, increased emphasis has been placed on community outreach, individualized education and treatment, and a continuum of care from birth through adulthood.

Federal Involvement

The Legislative, executive and judicial branches of the federal government have a history of activities that significantly affect the lives and welfare of the developmentally disabled.

Legislative

Major federal legislation concerning the developmentally disabled began with the creation of the Office of Education in 1868. During the 1920's, 30's and 40's influential legislation was passed dealing with vocational training, social security, and public health. Amendments to these laws in the 1950's specifically targeted the developmentally disabled as service recipients. The funding for these programs is provided in part by the federal government. The state and local agencies supply the service and finance the remaining cost.

Education. The basic aim of federal involvement in education has been to support and stimulate the development of local programming and to enhance the capacities of local institutions. In 1958, a bill passed, allocating funds for training educators of mentally retarded children, was the first piece of federal legislation to specifically address a handicapped group. Later bills expanded upon this one in terms of the agencies receiving funds, the aim of the funds, and the groups to be benefited.

In 1967 a Bureau of Education for the Handicapped was created within the Office of Education.

In 1975, with the passage of the Education for All Handicapped Children Act (Public Law 94-142), it was estimated that 1/2 of the nation's eight million handicapped children were not receiving an appropriate education, and that about one million of those students were excluded from the public school system entirely. The law provides that all handicapped children between three and 21 have available to them a free appropriate public education.

Vocational. Vocational training for the handicapped began with the Industrial Rehabilitation Act of 1920 which was established as a means of retraining disabled veterans of World War I. In 1943 amendments provided federal funds for the vocational habilitation of the deveopmentally disabled. Their share of the appropriated funds was not large, however, until 1965 amendments provided for the construction and staffing of habilitation workshops.

In 1963, a Vocational Act was passed targeted specifically for the developmentally disabled. The Vocational Education Act attempted to charge States with the responsibility for providing vocational training for the handicapped. As the bill seemed to have little effect, 1968 amendments required States to allocate ten percent of their basic grants for vocational education to handicapped persons. Further amendments passed in 1976 provide for the full cost of special programs and offer grants for construction of facilities, placement services, and the construction and operation of residential vocational schools.

Social Security. The Social Security Act of 1935 was established as a part of President Franklin Roosevelt's "New Deal". A 1957 amendment extended coverage to the developmentally disabled. A major restructuring of the social security processes in 1974 resulted in an expansion of services. For example, Title II of the Social Security Act provides disability insurance for employed persons and their families. If a developmentally disabled child's parents retire or die, he or she is eligible for payments, vocational habilitation services, and Medicare.

Title XVI of the Social Security Act authorized the Social Security Administration to provide minimum income benefits to the aged, blind, and disabled under a new Supplemental Security Income Program (SSIP). The program can be very important to the low income disabled, as beneficiaries receive other services such as Medicaid health care payments, social services and food stamps.

Public Health. Originally enacted in 1944, activities under Public Health Service include support to states and communities to encourage the development, construction and delivery of health services and facilities. The research activities of the Public Health Service are administered by the National Institutes of Health. Branches relevant to the developmental disabilities include: the National Institute of Mental Health, established in 1946; the National Institute on Neurological Diseases and Blindness established in 1950 (later changed to the National Institute on Neurological and Communicative Disorders and Stroke): and the National Institute of Child Health and Human Development (NICHD) established in 1962.

In 1961, the President's Panel on Mental Retardation, searching for an alternative to institutionalization, recommended comprehensive health services provided in community centers as a new approach. Their recommendations called for comprehensive coordinated state program planning.

The Developmental Disabilities Services and Facilities Construction Act of 1970 was generated by an ad hoc coalition representing the National Association for Retarded Citizens, the American Association for Mental Deficiency, the National Association of Coordinators of State Programs for the Mentally Retarded, the Council for Exceptional Children, the National Association of State Mental Health Program Directors, and United Cerebral Palsy. The group promoted usage of the term "developmentally disabled" in new legislation so that categorical legislation might be avoided and so the legislation would be noticeably distinct from efforts concerning mental health. The main intent of this act was "to assist the States to develop and implement a comprehensive and continuing State plan to meet the present and future needs of persons with developmental disabilities." The 1970 Act encouraged the provision of a range of services to meet the lifetime needs of the disabled.

The Developmentally Disabled Assistance and Bill of Rights Act of 1975 sought to iron out problems faced by the previous legislation. Title II of the 1975 Act has a strong advocacy emphasis. It enumerates a number of issues with regard to the rights of a developmentally disabled person. These include the individual's right to treatment, establishment of minimum standards for residential facilities, and the requirement that plans be drawn individually and updated annually for every client served through federally funded programs.

Executive

The executive branch of government has engaged in a series of White House Conferences addressing topics relevant to the developmentally disabled since the first 1909 White House Conference on the Care of Dependent Children. This conference set the precedent for the White House to serve as a forum for discussion of national concerns and also led to the creation of the Children's Bureau. Conferences on children and youth have been convened at intervals of approximately ten years ever since. Presidential Committees and Panels concerning handicapped interests have also been commissioned. Some of these have been established as permanent bodies. The conferences are instrumental in guiding national policy and legislation in the area of child welfare.

In 1947, The President's Committee on Employment of the Handicapped was convened. In 1949, the Committee was given permanent status. Established originally to help disabled war veterans, the Committee has since assumed responsibility to advise the President on matters concerning aspects of employment for all disabled persons.

In 1961, President Kennedy convened a panel of experts to address the subject of mental retardation. The panel published a report, "A Proposed Program for National Action to Combat Mental Retardation", which constituted a major milestone in improving services to the developmentally disabled.

President Kennedy called a White House Conference on Mental Retardation in September 1963 to present State representatives with the emerging Federal programs. In March 1966, by Executive Order President Johnson created a President's Committee on Mental Retardation as a continuing body to serve as a link between the White House and administrative departments on one level and also between the Federal government and local agencies on another.

Judicial

The developmentally disabled have been denied the rights enjoyed by other citizens through both laws and custom. Around the turn of the century laws were enacted which sought to curtail the freedom of the mentally retarded -- forbidding marriage, restricting place of residence, and permitting involuntary sterilization. Additionally, the lack of special resources, such as special education teachers or transportation, effectively precluded the developmentally disabled from obtaining an education and employment. Only recently have fundamental issues been raised concerning the legal and constitutional rights of developmentally disabled persons. Suits brought to court to test the legality of specific issues have served to establish broad principles of equal rights.

One result of the Civil Rights Movement of the 1950's and 60's has been an increasing concern about unconstitutional discrimination. Handicapped individuals also brought about law suits. Some of the more influential court cases have been:

1954 - Brown vs. Board of Education. In this famous case, the court decided that "separate but equal" educational programs were illegal and so required the desegregation of public schools.

1972 - Pennsylvania Association for Retarded Children vs. Commonwealth of Pennsylvania. The court decided in this case that public schools must provide every mentally retarded child with a free and accessible program of education and training. The decision led to the passage of legislation in 1974 (PL 93-380) requiring all States to develop plans for providing public education to every handicapped child regardless of degree of defect.

1972 - Wyatt vs. Stickney. The court stated a person has the right to individualized treatment in the least restrictive manner possible.

1973 - Souder vs. Brennan. This case established the right to be free from involuntary servitude in state institutions.

1973 - Urban League vs. Washington Metropolitan Area Transit Authority. In this case, the court ruled that special access to buildings and transportation systems must be provided for handicapped users.

1974 - Wyatt vs. Aderholt. This decision reverses the Supreme Court decision of 1927 by declaring compulsory sterilization illegal.

State of Illinois

In a slide presentation prepared at the Waukegan Developmental Center, Ralph Haynes said that Illinois has come "full circle" over the last century in its approach to and treatment of the developmentally disabled. This refers to the return of the developmentally disabled to care within a community setting, after years of institutionalization, isolation and misunderstanding. The history of the care and treatment of the developmentally disabled in Illinois is representative of, and has been greatly influenced by, national trends in this area. The commonly held attitudes and the policies of the last century in caring for retarded individuals have been influenced by parents' organizations, federal legislation, judicial action, research, and a large variety of other interested groups and sources.

In the early days of Illinois history, handicapped individuals were cared for by their own families. In 1865, the Illinois state legislature agreed to fund a school for "idiots and feeble minded" children. This first school was established with the goals of training students so that they might, upon leaving, better adapt to community life. At this time, in Illinois and in the nation, the problems of the handicapped had just begun to receive public attention. The school was viewed as experimental. It accepted only those students who were thought to be trainable and who would benefit from a learning environment.

The experimental Illinois school grew rapidly, with the demand far exceeding the number of available spots. (This situation was to characterize Illinois facilities for the next 100 years.) In five years time the school was granted permanent status by the Illinois legislators, named the Illinois Asylum for Idiots and Feebleminded Children, and moved to Lincoln, Illinois, where facilities were built. The school continued to accept only students thought teachable and was run much like a boarding school.

In 1880, however, the character of the Illinois Asylum for Feebleminded Children began changing. Pressure was put on the school to accept custodial cases. This was due to new attitudes towards mentally handicapped individuals, concerning the incurability of "feeblemindedness." As professionals and the public embraced this opinion, training efforts in institutions were reduced and the practice of warehousing began. By 1885, the twenty institutions in the nation were all rapidly becoming custodial in nature.

In 1910, the name of the Asylum for Feebleminded Children was changed to the Lincoln State School and Colony. In 1913, the population there exceeded 500 and in 1915, admission decisions were taken out of the hands of the superintendent of the institution and given to the court. The court policy was to admit any developmentally disabled citizen despite the extent of their handicap or age. These new policies served to stigmatize commitment and to make it increasingly difficult for persons to return to the community once they were committed.

The populations at Lincoln and a newly built institution for epileptics in Dixon, grew through the 1920's, 1930's and 1940's. They shared in the problems large custodial institutions were experiencing across the country. Facilities were crowded, staff/patient ratios were low, training was minimal and conditions were dehumanizing.

Concerns about conditions in institutions, human rights, alternatives to inpatient care, public school special education and a range of community programs were aired. Parents had organized in Dixon in 1951 and at Lincoln in 1954. These groups turned to the state legislators to lobby for better facilities and conditions. One result of their efforts was the 1959 construction of the Illinois State Pediatric Institute in Chicago. This 585 bed facility was designed to serve severely retarded children six and under. The Pediatric Institute was the first facility built for the retarded in Illinois since the Lincoln facility in 1877.

Illinois ranked 42nd out of 48 states on maintenance expenditures per resident in 1961. Progress was forthcoming, however. In 1964, with existing facilities overcrowded and waiting lists long, the Illinois legislators undertook a rapid expansion program, resulting in three 800 person capacity centers: The Warren G. Murray Center, in 1964; the William W. Fox Center in 1965; and the A. L. Bowen Center in 1966. In 1964, also, the American Association on Mental Deficiency presented the first standards for residential institutions for the retarded. The appearance of standards, the presence of new facilities, and various federal actions, caused concerned groups to assess the current situation and set objectives for the future. In Illinois, commonly agreed upon goals included new residential facilities for Northeastern Illinois as well as agreement that new facilities should not be larger than 400 beds, that Dixon and Lincoln should be reduced in size, that communities should be encouraged to provide services and that future facilities should be located in or near the disabled individual's home community.

In the 1970's, actions were taken towards these ends. In July 1970, an innovative "central intake program" was initiated at the Illinois State Pediatric Institute, to service the nine county area of Northeastern Illinois. The program was designed to evaluate and then direct clients on an individual basis to the proper combination of services they required. Clients are referred to services in their communities or when necessary, to state facilities for medical attention, care and financial aid. The emphasis of the program is on the primary community responsibility for care of the disabled. The Institute discontinued its long-term inpatient services, when this program got underway.

Another innovative project begun in 1972 was the construction of the Elizabeth Ludeman Center in Park Forest. This center was a radical departure from a conventional institution. Students at the Ludeman Center live in 50 ranch style homes, 8 students to a home. The Center emphasizes providing the students with a "normal" environment so that life within the center closely parallels life in the community. The Elizabeth Ludeman Center was one of the first of its kind in the nation. Two similar centers were built in Illinois: the William A. Howe Center, which opened in Tinley Park in 1973, and the Waukegan Developmental Center, which opened in Waukegan in 1975.

By the time Waukegan and Howe were well under construction the concept of residential care had changed again. It was felt that even they were too large. The state began to encourage the development of smaller facilities, closer to families, which maximized use of community based services.

The federal Developmentally Disabled Assistance and Bill of Rights Act of 1975 requires every state to set up a Governor's Council on Developmental Disabilities. The Illinois Council, an advisory and planning board, is composed of members from state agencies which work with issues concerning the disabled, and other community representatives. The agencies most actively involved are The Department of Mental Health and Developmental Disabilities, the Illinois Office of Education, and the Illinois Board of Vocational Rehabilitation.

In Illinois, institutions are no longer crowded and the state can boast of having more facilities accredited by the Joint Commission on Accreditations of Hospitals than any other state. As of January, 1977, Illinois held the number one rank in the quality of services provided for its developmentally disabled citizens. More persons are being served and new programs developed with community care and normalization being stressed. With the backing of the federal and state governments, the courts and numerous national organizations, the future of care for the developmentally disabled in Illinois now seems quite dependent on community initiative and response in accepting responsibility and providing support for the handicapped in their areas.

Lake County

The needs of the developmentally disabled were first recognized in Lake County by private citizens. Small private classrooms for the education of the developmentally disabled were started in the 1950's. One history of these early days has been documented by Virginia F. Matson in A School for Peter. The book explains the founding and growth of the Grove School where Virginia Matson continues to serve as president. The process for other private schools in Lake County is undoubtedly similar, but their histories remain unwritten. An experienced teacher of normal children Virginia Matson undertook the task of instructing the developmentally disabled brother of one of her pupils. Word of her success spread quickly and another developmentally disabled child joined her special Saturday class. She resigned her regular position and began teaching a small group in her own home, with tuitions paid by the local districts. Classroom materials and techniques were invented and volunteers began to assist. In 1960 the program moved into an abandoned, rural, brick school house and was equipped by private donations. Help from churches and school boards was inconsistent. Sometimes assistance was available; other times, nothing. In 1965 the school was moved to its present location where it now provides residential and vocational services, in addition to special education.

Another history is provided by Robert Terese and Corinne Owen's account of the Lambs, a work and residential environment for developmentally disabled adults. In their book, A Flock of Lambs, they describe the start of their business work/training center in 1961 with a pet shop in downtown Chicago. In 1966, the Lambs moved to its present Lake County location, Libertyville. Acquisition of the farm site allowed the Lambs to diversify their business and work opportunities. The barn houses an expanded pet shop, the main farm house became a restaurant, a machinery shed became a gift shop, and the garage was converted into a bakery. Living facilities and other work centers were added. The Lambs functions as a business employing developmentally disabled adults, as a residential program for some, and as an educational program for the general public. The philosophy of the Lambs has been implemented in other states for individual businesses, such as a craft shop in a shopping center.

Other facilities in Lake County also started small and have expanded to meet growing demands.

What is now Klingberg Residential School began in 1954 when Irene Klingberg taught a class of developmentally disabled children in a church basement. The humble beginnings of that day school were expanded into a residential school for over 100 children after it moved to its present farm site in 1962. Klingberg continues to provide a residential setting with an educational emphasis. A sheltered workshop handles industrial contracts and provides prevocational training in silkscreening and ceramics.

In 1954 the Glenkirk Association for the Retarded was started by a group of people, mostly parents. At first the day care school for the trainable retarded of the Glenview community in Cook County was operated in a church. A school building was opened in 1960 for the day program, and property was purchased in 1971 for a residential program. It took seven years to meet the guidelines for residential facilities and obtain all the necessary clearances. In 1978, the Glenkirk Association opened the remodeled residential home in Lake Forest for children between the ages of six and twenty-one. All residents attend special education programs in public schools during the day.

In 1953, Countryside Farm School began its program with five mentally retarded students on a farm belonging to the mother of one of the children, a trainable mentally handicapped boy. In 1954 the school was incorporated as Countryside Center for the Retarded. In 1969 with the addition of a Workshop program, the name was changed again to its present Countryside Center for the Handicapped. Countryside is a private, not-for-profit corporation serving over 200 mentally retarded, physically or emotionally handicapped children and adults from northern Cook and Lake counties. Their extensive programming includes an adult training program, two rehabilitation workshops, a follow-along program for developmentally disabled adults in the community, and a family support unit.

Mount Saint Joseph is a residential facility for adult developmentally disabled women. It began in 1935 with 12 residents in an old farmhouse. Located on 160 acres, it includes a farm and residential cottages. Habilitation classes, therapy and recreation are offered. It has always been operated by the Daughters of St. Mary of Providence.

Begun in 1967 as Riverside Manor, a nursing home for profit, the name was changed in 1976 to Riverside Foundation when it became a not-for-profit community organization. Located in Lincolnshire, Riverside is an intermediate care facility for developmentally disabled adults. In addition to special programs at the facility some residents work at the Countryside Center in Barrington and at the Robert A. Flood Work Activity Center in Zion.

The newest residential facility in Lake County is the Moraine Association's community living facility in Highland Park for developmentally disabled adults. It was started by a small group of parents who became acquainted in 1974 because the special recreation district had planned such vigorous social programs for young adults that the parents were all involved in car pools for the group. The Moraine Association's facility reflects the trend to community-based services. The six-apartment unit for twenty adults is situated on a residential street. Recreational and laundry facilities were purposefully not included to encourage residents to go out into the community for these activities.

From the early days of these private programs, the size of parent groups grew and contracted as needs changed. For example, the Lake County Society for the Retarded began over 25 years ago when a man from Zion put an advertisement in the Waukegan paper to the effect that he had a retarded child, had a problem, and that there would be a meeting. The Society was born when 25-30 people came, donated start-up funds, hired a retired teacher, and opened a classroom in a church basement in Zion. During the first decade the Society grew until about a dozen classes were being operated around the County. As public school special education districts began to take over the education of developmentally disabled children, the Society concentrated on work activities for the adult population. Today the Robert A. Flood Work Activity Center in Zion provides work and activities for over 150 developmentally disabled adults.

During the 1959-60 school year, those school districts located in the center and northeast area of Lake County studied the need for comprehensive special education services and how they could be provided. In January of 1960, a cooperative joint agreement was created and named the Special Education District of Lake County (SEDOL). SEDOL's enrollment grew from 41 students in the 1960-61 school year to 2,683 students in the 1977-78 school year. For an additional 60 - 70 students who are better served by existing private programs, SEDOL funds their education through private programs. In 1975, Laremont School in Gages Lake was built to serve 300 moderately and multiply handicapped children. The history of SEDOL will now be written in terms of programming changes instead of movements among temporary facilities.

A second special education school district, Northern Suburban Special Education District (NSSED), serves communities in southeast Lake County and northeast Cook County. The 23 school district cooperative designed Stratford School to meet the special needs of moderately and multiply handicapped children. The Stratford School was made possible by the efforts of a Task Force of parents and citizens appointed by the participating school boards. This group took responsibility for all the steps involved, up to and including the recommendation of a site and an architect. The curriculum at Stratford School focuses on functional tasks and their application to life experiences. A second entity, the Stratford Center, provides diagnostic, supervisory, and administrative services to the member school districts.

The third special education school district, Waukegan Public School District #60 is a unit school district. It is a community-based district and this attitude is reflected throughout all its programming. Prior to the later 1960's moderately developmentally disabled children had been completely segregated on the playground and during lunch as well as in special education classes. With the implementation of the West Plan all that changed. Children were considered to be students first and then their exceptionality was considered second. All students are programmed individually and to the maximum of their abilities spend part of each day in regular classes. The Waukegan Early Entry (WEE) Program combines training parents in a home intervention program with an early childhood learning center. The Waukegan Early Evaluation Program (WEEP) is a screening of developmental tasks administered to kindergarten students to identify children who need special curriculum planning. The Bilingual Individualized Program Assessment in Spanish (BIPAS) provides an instructional resource service for those developmentally disabled students for whom English is a second language. Lincoln School for the severely and profoundly retarded offers day services for children living with their families and children living at the Waukegan Developmental Center.

The Waukegan Developmental Center has 48 duplex homes on a 36-acre campus close to downtown Waukegan. The center provides residential, therapeutic and educational services for close to 400 developmentally disabled children and adults. Opened in 1975 the home at Waukegan Developmental Center is a place where residents learn many of the skills necessary for a more independent life. Intensive training begins with such self-care skills as toileting, dressing, eating and personal hygiene. Younger residents who have mastered these basic skills attend daily special education classes in community programs; older residents attend workshops located on campus and in the community. The Center-community partnership is reflected in all areas of programming.

The Lake McHenry Regional Program (LMRP) was designed to supplement regular and special education services to the two counties. It provides highly specialized types of evaluation which are not economically feasible for local schools or special education districts to provide. Between 1969 and 1974, equipment was purchased for audiological testing and a pre-school vision and hearing program was started. More professionals were added as the program grew, including a social worker, a speech and language clinician, another audiologist, and a psychologist. In 1975 the comprehensive diagnostic center was implemented. Some services provided are: physical and occupational therapy, early childhood diagnostic screening, and a Parent-Infant Education Program to serve developmentally disabled children below the age of three.

Since 1974 the Lake-McHenry Regional Consortium Board has met to discuss existing programs and services, and to identify unmet needs of the region's population. Continued contacts with other agencies, programs, and representatives maintain community involvement.

As you develop new programs and continue to make history in the County, State and nationally, we hope you will keep a written record to update and improve this chapter and to provide guidelines for others who will follow you.

Recommended for Further Reading

Gray, Mary Z. 1977 — Mental Retardation Past and Present. Washington, D.C.: President's Committee on Mental Retardation (PCMR). Traces the history of the treatment of retarded persons in the United States from the humanitarian movement of the 1850's to the present. Supported by many photographs and written at a non-technical level. Part of a four-volume series published by PCMR.

Kanner, Leo. 1964 — A History of the Care and the Study of the Mentally Retarded. Springfield, Illinois: Charles C. Thomas. Carefully documented history of the beginning of care for the developmentally disabled. Traces the origin of new ideas and practices as they spread, geographically and over time throughout the countries of the world.

Matson, Virginia. *A School For Peter*. Carol Stream, Illinois: Creation House.
1974 The autobiographical account of the development of Grove School in Lake County, Illinois. Describes its humble beginnings in the late 1950's in the author's home through its operation as a residential and educational facility for the developmentally disabled in the early 1970's.

Sloan, William and Harvey A. Stevens. *A Century of Concern: A History of the American Association on Mental Deficiency 1876-1976*. American
1976 Association on Mental Deficiency, Inc., 5201 Connecticut Ave., N.W., Washington, D.C. 20015.
Each of the ten decades covered by this volume is dealt with in a separate chapter. The 300-page history of the Association, the largest of the professional organizations for the developmentally disabled, traces three major themes: the changing concept of mental retardation, its improvability or curability, and the relationship between mental retardation and social behavior.

Terese, Robert, with Corrine Owen. *A Flock of Lambs*. Chicago: Henry
1970 Regnery Company.
A series of episodes and incidents in the authors' nine years of association with developmentally disabled adults. It begins with the opening of a pet shop in downtown Chicago where the developmentally disabled adults worked. Expansion led to the development of the Lamb's Farm in Libertyville, Illinois.

Wolfensberger, Wolf. *The Origin and Nature of Our Institutional Models*.
1975 Syracuse, New York.
Chronicles the attitudes, hopes, and policies that led to the creation of institutions for the mentally retarded. Explores common perceptions of the mentally retarded, such as pitiable, sick, menacing, innocent, angelic, and, only rarely, as developing persons. Critiques institutions and explains the ideologies and assumptions that underlie them.

Directory of Services for Families in Lake County, Illinois

This is a directory of all the services in Lake County, Illinois for the developmentally disabled persons. Also included are those services outside Lake County which are available and frequently utilized. Although all the information has been carefully compiled and checked, errors are probably inevitable. We would appreciate these being drawn to our attention to improve the utility of subsequent printings of the handbook.

Services are listed in alphabetical order with addresses and telephone numbers as of Summer 1979. A brief description of programs is provided for each service.

An index precedes the alphabetical listing. The index is organized in a parallel format to the Sections and Chapters of the handbook. Services are listed under more than one heading as applicable. Special terminology is explained in the text; the explanations are not repeated for brief program descriptions in the directory. To use the directory most effectively we recommend first reading the corresponding Chapters of the handbook.

INDEX TO DIRECTORY OF SERVICES

Life Course Planning

Diagnosis and Assessment

Achievement Center
Chicago Osteopathic Medical Center
Children's Center for Learning
Children's Memorial Hospital
Children's Therapeutic Programs
Division of Services for Crippled Children
Epilepsy Rehabilitation Institute
Evanston Hospital
Glenbrook Hospital
Illinois Department of Mental Health and
    Developmental Disabilities Subregion 7 -- Developmental
    Disabilities Division
Illinois Institute for Developmental Disabilities (IIDD)
Lake McHenry Regional Program (LMRP)
Loyola University Medical Center
Lutheran General Hospital
Mercy Hospital and Medical Center
Michael Reese Hospital and Medical Center
Northwestern University Memorial Hospitals
Presbyterian-St. Luke's Hospital
Rehabilitation Institute of Chicago
Schwab Rehabilitation Hospital

Shriner's Crippled Children's Hospital
Wyler's Children's Hospital of the University
of Chicago
University of Illinois Hospitals

Professionals Involved with Special Education

(No services applicable)

Education for the Developmentally Disabled

College of Lake County
Glenkirk Association for Retarded Citizens
The Grove School
Illinois Office of Education
Lake County Head Start
Lake-McHenry Regional Program (LMRP)
Low Incidence Cooperative Agreement (LICA)
Northern Suburban Special Education District (NSSED)
Special Education District of Lake County (SEDOL)
Trinity College
Waukegan Unit School District #60 -- Special Education Services

Religious Education

Congregation B'nai Tikvah
First Congretional Church
Immaculate Conception Church
Immanuel Baptist Church
Messiah Lutheran Church
North Suburban Synagogue - and Beth El
Saint Andrew's Lutheran Church
Saint Dimas Church
Saint Joseph Church -- Libertyville
Saint Joseph Church -- Round Lake
Saint Mary's Church -- Buffalo Grove
Saint Mary's Church -- Lake Forest
Santa Maria del Popolo
Waukegan Developmental Center

Vocational Services

Clearbrook Center
Countryside Center
Glenkirk Association for Retarded Citizens
The Grove School
Illinois Department of Rehabilitation Services (DRS)
Illinois State Job Service
Kenosha Achievement Center

Lake County Area Vocational Center (LCAVC)
Lake County Comprehensive Employment and Training Act (CETA) Program
Lake County Society for the Retarded
The Lambs, Inc.
McHenry County Association for Retarded Citizens
North Shore Association for Retarded Citizens
Northwest Suburban Aid for the Retarded
Opportunity, Inc.
President's Committee on Employment of the Handicapped
Saint Coletta

Living Environments

Elaine Boyd Creche
Glenkirk Association for Retarded Citizens
Illinois Children's Hospital-School
Illinois Department of Mental Health and Developmental Disabilities Subregion 7 -- Developmental Disabilities Division
Klingberg School
The Lambs, Inc.
Little City Foundation
Marklund Home
McHenry County Association for Retarded Citizens
Misericordia North
Moraine Association
Mount Saint Joseph
Orchard Village
Riverside Foundation
Saint Coletta
Waukegan Developmental Center

Family Support

Health Care Services

Chicago Eye, Ear, Nose and Throat Hospital
Chicago Osteopathic Medical Center
Condell Hospital
Easter Seal Society of Lake County, Inc.
Feingold Association
Good Shepherd Hospital
Highland Park Hospital Foundation
Hyperactive Children's Institute -- Feingold Association of Illinois
Illinois Masonic Medical Center
Lake County Crippled Children, Inc.
Lake County Health Deptment

Lake County Physician's Referral of the Lake County Medical Society
Lake Forest Hospital
Lake-McHenry Regional Program (LMRP)
McHenry Hospital
Medi-Check International Foundation, Inc.
Michael Reese Hospital and Medical Center
National Foundation of Dentistry for the Handicapped
Northwestern University -- Frances Searle Building
Patient Prescription Information, Inc.
Saint Therese Hospital
Veteran's Administration Hospital
Victory Memorial Hospital
Zion-Benton (American International) Hospital

Family Counseling

Epilepsy Foundation of America -- North Shore, Lake County Chapter
Family Service Agency of North Lake County
Family Service Agency of South Lake County
Lake County Health Department
Youth and Family Counseling

Recreation

Botanic Garden of the Chicago Horticultural Society
Boy Scouts of America
Camp Fire Girls - Lake County Council
Camp Henry Horner
Camp New Horizons
Center for Enriched Living
Creative Children's Arts
Friends of Handicapped Riders
Girl Scouts
The Learning Exchange
Little City Foundation
Northeastern Illinois Special Recreation Association (NISRA)
Northern Illinois Special Recreation Association (NISRA)
Northern Suburban Special Recreation Association (NSSRA)
Northwestern Special Recreation Association (NWSRA)

Peacock Camp for Crippled Children
Ray Graham Association's Camp Saint Francis
YMCA's and YWCA's

Community Services

Catholic Charities -- Lake County Office
Connection Telephone Counseling and Referral
Countryside Center for the Handicapped
Disabled Individual's Assistance Line (DIAL)
FISH
Fox Valley Home Health Service, Inc.
Glenkirk Association for Retarded Citizens
Jewish Family and Community Service
McHenry County Association for Retarded Citizens
North Shore Help Line
North Suburban Self Help Center
Parental Stress Services (Citizen's Committee for Children and Parents under Stress)
Regional Transportation Authority

Financial Planning

Guardianship and Advocacy Commission
Lake County Bar Association -- Lawyer Referral Service
Lake County Department of Public Aid
Social Security Administration

Some Considerations about Having More Children

The American College of Obstetrics and Gynecologists
Evanston Hospital
Lutheran General Hospital
Northern Illinois Chapter -- American Society of Psychoprophylaxis in Obstetrics, Inc. (Lamaze)
Rockford Memorial Hospital
Society for the Protection of the Unborn through Nutrition (SPUN)

Consumer Action

Parents and the Needs of Children at Home

Illinois Bell Telephone -- Services for the Handicapped
Lake McHenry Regional Program (LMRP)

Parent's of Children in Programs

(see Education for the Developmentally Disabled)

Parents as Members of Parents' Organizations

American Association for the Education of the Severely/Profoundly Handicapped (AAESPH)
American Association on Mental Deficiency (AAMD)
Coordinating Council for Handicapped Children (CCHC)
Council for Exceptional Children (CEC)
Down's Development Counsel
Down's Syndrome Congress
Epilepsy Foundation of America - North Shore, Lake County Chapter
Hyperactive Children's Institute - Feingold Association of Illinois
Illinois Alliance for Exceptional Children and Adults
Illinois Association for Retarded Citizens
Illinois Society for Autistic Children
Illinois Regional Resource Center
National Association for Down's Syndrome (NADS)
National Association for Retarded Citizens (NARC)
National Easter Seal Association for Crippled Children and Adults
National Foundation -- March of Dimes
National Society for Autistic Children (NSAC)
Parents' Campaign for Handicapped Children and Youth
President's Committee on Employment of the Handicapped
President's Committee on Mental Retardation
Self-Help Development Institute
United Cerebral Palsy of Greater Chicago

Parents as Planners of Programs

Health Systems Agency for Kane, Lake and McHenry (HSA/KLM)
Illinois Governor's Planning Council on Developmental Disabilities
Lake County Coordinating Council for Mental Health, Substance Abuse, and Developmental Disabilities
Lake County Special Education Advisory Committee
Subregion 7 Developmental Disabilities Services Act (DDSA) Planning Committee
United Way of Lake County, Inc.

Parents as Legal and Legislative Advocates

Advocates for the Handicapped
Coordinating Council for Handicapped Children (CCHC)
Guardianship and Advocacy Commission
Illinois Commission on Mental Health and Developmental Disabilities

Illinois Developmental Disabilities Advocacy Authority
Illinois Developmental Disabilities Law Project
Illinois Office of Education
Lake County Bar Association -- Lawyer Referral Service

ALPHABETICAL DIRECTORY OF SERVICES

ACHIEVEMENT CENTER
Box 267, Grayslake, IL 60030 223-0333*

Provides educational and psychological diagnosis, remediation and tutoring of educably mentally handicapped, brain damaged and learning disabled children. Work in conjunction with schools but are strictly private; parents must pay fees. Suggest that parents go to school district first, use program as secondary source.

ADVOCATES FOR THE HANDICAPPED
2200 Merchandise Mart, Chicago, IL 60654 822-0435

Conducts investigations, gives testimony at public hearings, suggests changes in policy or law, conducts public education programs, provides direct service through its Legal Program, and publishes a bi-monthly newsletter, ADVOCATOR. Membership open to all interested in advocating for all the handicapped.

AMERICAN ASSOCIATION FOR THE EDUCATION OF THE SEVERELY/PROFOUNDLY HANDICAPPED (AAESPH)
Membership Coordinator, 1600 West Armory Way, Garden View
Suite, Seattle, WA 98119

Dedicated to provide quality education, advocate, disseminate information and materials about severely and profoundly handicapped children. Publishes a newsletter and a quarterly journal.

AMERICAN ASSOCIATION ON MENTAL DEFICIENCY (AAMD)
5201 Connecticut Avenue, N.W., Washington, D.C. 20015

Oldest organization of professionals and parents who work with the developmentally disabled. Publish several journals and provide information on the latest advances in treatment of the developmentally disabled.

THE AMERICAN COLLEGE OF OBSTETRICS AND GYNECOLOGISTS
1 East Wacker Drive, Chicago, IL 60601 222-1600

Provides information on proper nutrition for expectant mothers and lists obstetricians and gynecologists for each community.

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*All telephone numbers are Area Code 312, unless otherwise indicated.

BOTANIC GARDEN OF THE CHICAGO HORTICULTURAL SOCIETY

P.O. Box 400, Glencoe, IL 60022 835-5440

Has a model garden for the disabled gardener and provides instruction in horticultural therapy--the use of gardening for improvement of physical and mental well-being.

BOY SCOUTS OF AMERICA

Northeast Illinois Council, 724 Vernon Avenue, Glencoe, IL 60022

Special units attached to schools in Highland Park, Waukegan, Grayslake, and Northbrook. Covers the general area of eastern Lake County, call Paul Totzke at 835-4142.

Northwest Suburban Council, 1300 East Rand Road, P.O. Box 968,
Arlington Heights, IL 60006

Covers southwestern area of Lake County though has no special units at this time, call Joe DeKeyser at 394-5050.

CAMP FIRE GIRLS -- LAKE COUNTY COUNCIL

111 Oak Knoll Drive, Lake Villa, IL 60046

No special units at this time but willing to help organize. Call Donna Monnier at 356-7579.

CAMP HENRY HORNER

P.O. Box 232, Round Lake, IL 60073

Summer camp for mentally retarded children and adults run by the Young Men's Jewish Council. Call Dan Fareniella at 546-4435 or the Center for Enriched Living, 679-8490.

CAMP NEW HORIZONS

3042 Holdridge, Waukegan, IL 60085

Privately run summer camp for physically handicapped and learning disabled children at the Phantom Lake YMCA Camp, Mukwonago, WI (near Milwaukee, WI).

CATHOLIC CHARITIES -- LAKE COUNTY OFFICE

4 South Genesee Street, Waukegan, IL 60085 623-1860

Multifunctional agency providing services such as counseling, foster care, adoptions, and Spanish advocacy.

CENTER FOR ENRICHED LIVING

9301 Gross Point Road, Skokie, IL 60076

Provides recreation and social activities for young adults with developmental disabilities. Call Lynn Albanese at 679-8490.

CHICAGO EYE, EAR, NOSE AND THROAT HOSPITAL
231 W. Washington Blvd., Chicago, IL 60605 372-9400 Clinic ext. 35

Special clinics deal with allergies, podiatry and audiology, used by handicapped, especially.

CHICAGO OSTEOPATHIC MEDICAL CENTER
5200 S. Ellis Avenue, Chicago, IL 60615

Multiple Services:

(1) Pediatric Comprehensive Care and Prevention Program (PCCP) Room 1128
Screening and remediation program designed for children with learning and/or behavioral problems which interfere with the child's ability to function adequately. Judith Allen, Project Director, 947-4749.

(2) Hospital and outpatient clinic. Uses wholistic approach to treating the patient by acknowledging the relationships of the body with the mind and emotions. Emphasizes fact that the human body has the inherent capacity to heal itself. Therapy involves manipulating the neuromuscular framework to help the body return to its healthy state, 947-3000.

CHILDREN'S CENTER FOR LEARNING
National College of Education, 2532 N. Asbury, Evanston, IL 60201
256-5150 ext. 363/368/369

Director: Chris Johnson.

Provides educational and psychological diagnosis for educably mentally handicapped and learning disabled children grades K-10. Remedial services offered but parents must provide transportation for sessions held 2-3 times per week. Operate summer program.

CHILDREN'S MEMORIAL HOSPITAL
2300 Children's Plaza West Fullerton Parkway, Chicago, IL 60614

Child Psychiatry Division (649-4589) does psychological, neurological, speech and language, and educational testing. If child needs more testing, they refer to the 31 specialty clinics and coordinate the services through Child Psychiatry. Cost: approximately $700, green card accepted, but no sliding fee scale. Make contact with Social Worker. Sometimes waiting list is 3 months long.

CHILDREN'S THERAPEUTIC PROGRAMS
715 Lake Street, Oak Park, Il 60301 383-3800

Medical Director: Paul J. Dunn

Multi-disciplinary.
Diagnostic and treatment program for children with varying disabilities. Neurological, psychological, visual, audiological and osteopathic (relationship of muscles and bones to the rest of the body). Examinations are done to evaluate and diagnose child. Treatment consists of some of the following: home treatment, group treatment at center, individual treatment at center, diet supplements, and family counseling.

CLEARBROOK CENTER
3201 Campbell Road, Rolling Meadows, IL 60008 255-0120

Among other programs provided, has a rehabilitation workshop for developmentally disabled adults. Located at 680 Lively Boulevard, Elk Grove Village, IL 60007, phone 593-0700.

COLLEGE OF LAKE COUNTY
19351 Washington Street, Grayslake, IL 60030 223-6601

Provides post secondary education including: general education courses, career programs, continuing education and community service programs. May begin classes for developmentally disabled adults soon.

CONDELL HOSPITAL
Cleveland and Stewart, Libertyville, IL 60048 362-2900

No specialized programs for developmentally disabled.

CONGREGATION B'NAI TIKVAH
795 Wilmot Road, Deerfield, IL 60015 945-0470

Provides special religious education.

CONNECTION TELEPHONE COUNSELING AND REFERRAL
1125 North Milwaukee Avenue, Libertyville, IL 60048
Crisis phone: 367-1080 Office phone: 362-3381

Provides counseling, referral and information to all people in any type of crisis who call for help.

COORDINATING COUNCIL FOR HANDICAPPED CHILDREN (CCHC)
407 South Dearborn Street, Room 680, Chicago, IL 60605 939-3513

Serves the Chicago metropolitan area, including Lake County, as an advocacy organization for handicapped children and their families. Publishes a newsletter, offers free training sessions for parents and professionals, and holds monthly meetings. Is the Parent Information Center for the Midwest region.

COUNCIL FOR EXCEPTIONAL CHILDREN (CEC)
1920 Association Drive, Reston, VA 22091

Parents and professionals' organization providing information, referrals, publications, and training. The Illinois Federation is located at 591 Walnut Lane, Elk Grove Village, IL 60007, phone 541-4434.

COUNTRYSIDE CENTER FOR THE HANDICAPPED

P.O. Box 412,Barrington, IL 60010 438-3855

Executive Director: Ralph Walberg

Provides a wide variety of vocational and supportive services to persons with developmental disabilities over the age of 16 and their families. The facility on Shirley Road in Palatine houses administration offices, adult training programs, the rehabilitation workshop, a Follow Along Program to keep track of clients served and provide smooth transition to another facility, and the Family Support Unit. The Vocational Rehabilitation Center of North Lake County, 821 Tenth Street, North Chicago is another Countryside Center program.

CREATIVE CHILDREN'S ARTS

614 Lincoln Avenue, Winnetka, IL 60093 446-7260

Teaches the visual and musical arts to children and has special classes for cerebral palsied and retarded children. Classes are held after school and on Saturdays.

DISABLED INDIVIDUAL'S ASSISTANCE LINE (DIAL)

793-5000

Sponsored by the Illinois Department of Rehabilitation Services as a community information and referral for all kinds of handicapped needs.

DIVISION OF SERVICES FOR CRIPPLED CHILDREN

Region Office: 43 E. Ohio, Chicago, IL 60611 996-3563

State and federally funded medical service agency administered by the University of Illinois providing specialized medical care and related rehabilitative services to children with orthopedic conditions, cerebral palsy, epilepsy, spina bifida, phenylketonuria (PKU). Services include: diagnostic evaluation, consultation; speech, hearing, physical and occupational therapies; appliances such as braces, limbs, and hearing aids. Clinics for diagnostic testing are held in different hospitals around the state.

DOWN'S DEVELOPMENT COUNSEL

P.O. Box 118, Grayslake, IL 60030 746-5076

President: Ruth Collins

Matches parents of older children with Down's Syndrome with parents of newborn children with Down's Syndrome to help the new parents cope. Provides information and material to interested parents.

DOWN'S SYNDROME CONGRESS
Membership Chairman, 118 Paloma Drive, San Antonio, TX 78212

National organization seeking to promote the welfare of persons with Down's Syndrome.

EASTER SEAL SOCIETY OF LAKE COUNTY, INC.
1125 North Milwaukee Avenue, Libertyville, IL 60048 367-1750

Provides speech and language therapy and evaluation and therapy for handicapped children and adults. Offers free loan of hospital equipment such as wheelchairs, hospital beds, crutches and walkers.

ELAINE BOYD CRECHE
Bloomingdale, IL 60108 529-3350

Administrator: Jacklynne Pettitt

A private residential facility serving nonambulatory children functioning at the severe and profound levels of retardation from birth through the age of eighteen.

EPILEPSY FOUNDATION OF AMERICA -- NORTH SHORE, LAKE COUNTY CHAPTER
614 Lincoln Avenue, Winnetka, IL 60093 441-7560

Local chapter of the Chicago Metropolitan Chapter provides individual, family, and group counseling. Monthly self-help groups and a consumer council. Membership benefits: low cost drugs, term life insurance, medical alert jewelry. Chicago office: 22 West Monroe, Chicago, IL 60603, phone 332-4107. National office: 1828 L Street N.W., Suite 406, Washington, D.C. 20036, phone 202-293-2930.

EPILEPSY REHABILITATION INSTITUTE
5825 Cermak Road, 5th Floor, Cicero, IL 60650 652-3581

Two new programs at E.R.I. will provide a 6 to 12 week, 24 hour program (day program available in some cases) for individuals 18 years and older who are having frequent seizures and/or are experiencing a number of difficulties in dealing effectively with problems associated with their epilepsy. One program will serve the intellectually alert, and the other will serve the developmentally disabled in need of a slower-paced program. The programs will include neurological work-ups and treatment, monitoring of anticonvulsant drug levels, intensive individualized educational and activity programs, psychological and intellectual assessment, individual and group counseling, employment information, vocational training and further education.

EVANSTON HOSPITAL

2650 Ridge, Evanston, IL 60201 492-2000

Multiple services: (1) Perinatal Center for newborn children with critical troubles (such as prematurity and birth defects). Perinatal center has special staff and equipment.
(2) Evaluation Center for Learning - comprehensive diagnostic service and short-term therapy for children having developmental, academic, or school adjustment problems (for children older than 3). Carol Ceithaml, Associate Director.
(3) Continuing Assessment Program - comprehensive interdisciplinary diagnostic service for 0-3 year olds who are thought to have developmental disabilities. Tracks children who were in perinatal center. All testing done at hospital. Full cost ranges from $200-600. Total of 14-21 days for full cycle of referral, testing and recommendation. Treatment takes longer depending on the child. Affiliated with Northwestern University Medical School and Children's Memorial Hospital.
(4) Genetic Counseling

FAMILY SERVICE AGENCY OF NORTH LAKE COUNTY

319 North County Street, Waukegan, IL 60085 662-4464

Provides professional counseling for marriage problems, parent-child conflicts, total family difficulties and individual personality adjustment problems. Outreach offices at 200 North Milwaukee Avenue, Lake Villa, IL 60046, phone 356-1944, and at Shiloh Village, 2725 Sheridan Road, Suite 16, Zion, IL 60099, phone 872-4388.

FAMILY SERVICE AGENCY OF SOUTH LAKE COUNTY

777 Central Avenue, Highland Park, IL 60035 432-4981

Provides professional counseling for marriage problems, parent-child conflicts, total family difficulties, and individual personality adjustment problems. Outreach offices at 202 South Cook Street, Barrington, IL 60010, phone 381-4981 and Route 83 and Diamond Lake Road, Mundelein, IL 60060, phone 949-5090.

FIRST CONGRETIONAL CHURCH

315 North Utica, Waukegan, IL 60085 336-5368

Will provide special religious education if there is demand for it.

FISH

Barrington, IL 60010 381-7474 and Deerfield, IL 60015 498-1231

Provides emergency transportation for the needy, handicapped, and elderly to and from medical, dental and mental health appointments in addition to other transportation on an emergency or need basis. Provides emergency baby-sitting, in-home care, meals, grocery shopping and aid to disaster victims. 24 hour a day answering service.

FOX VALLEY HOME HEALTH SERVICE, INC.
7½ South County Street, Waukegan, IL 60085 662-0120/0121/0122

Health care in the home under the direction of a physician. Services include part-time nursing care by a registered nurse, home health aid and physical, speech or occupational therapy. 24 hour answering service.

FRIENDS OF HANDICAPPED RIDERS
5923 West Barry, Chicago, IL 60634

Provides horseback riding for physically and mentally handicapped people. One of the stables sponsoring the program is the LorBar Ranch in Libertyville, IL. Call Nancy Wise at 637-1911.

GIRL SCOUTS
Lakeview Council, 732 North Genesee Street, Waukegan, IL 60085

Has one special troop in Grayslake and may start one in Waukegan. Services north and northeastern Lake County. Call Jody Evans at 662-5725.

Moraine Council, 747 Deerfield Road, Deerfield, IL 60015

One special troop in Highland Park. Services Mundelein, Buffalo Grove and all towns east to Lake Michigan. Call 945-7750.

Sybaquay Council, 15 Ziegler Court, Elgin, IL 60120

Serves southwestern Lake County but has no special troops at this time.

GLENBROOK HOSPITAL
2100 Pfingsten, Glenview, IL 60025 729-8800

Sister hospital of Evanston Hospital. See Evanston Hospital.

GLENKIRK ASSOCIATION FOR RETARDED CITIZENS
701 Harlem Avenue, Glenview, IL 60025 729-6870

Provides a variety of services to residents of northern Cook County and southern Lake County. Offers an early intervention program for parents of infants with developmental delays; a school providing education for the more severely developmentally disabled child ages 3 to 21; a work activities program for adults; a residential facility, the Glenkirk Home in Lake Forest, for ambulatory children between the ages of 6 to 14 who attend special education classes in the community; and respite services for developmentally diabled children and adults.

GOOD SHEPHERD HOSPITAL
Barrington, IL 60010

New hospital scheduled to open Fall 1979.

THE GROVE SCHOOL
40 East Old Mill Road, Lake Forest, IL 60045 234-5540

Director: Virginia F. Matson

Provides special education services for severely and profoundly handicapped children ages 3 to 21 who cannot be served in public school facilities. Offers prevocational training for severely and profoundly handicapped young adults ages 16 to 21. Skilled nursing facility houses 45 multiply handicapped children and adults.

GUARDIANSHIP AND ADVOCACY COMMISSION
1 West Old State Capitol Plaza, Suite 917, Springfield,
IL 62701 217-785-1541

A State agency established January 1, 1979 comprised of nine members. Directed to establish legal counsel to eligible persons and enforce rights or duties; set up regional panels to investigate and complain when persons' rights are being violated; and serve as a guardian to persons declared incompetent who have no one to function in that capacity.

HEALTH SYSTEMS AGENCY FOR KANE, LAKE AND McHENRY (HSA/KLM)
188 South Northwest Highway, Cary, IL 60013 639-0061

Director: Richard Janishewski

Federally funded organization designed to develop plans for future health services in the three county areas, including services for the developmentally disabled. Council for Lake County identifies health needs.

HIGHLAND PARK HOSPITAL FOUNDATION
718 Glenview Avenue, Highland Park, IL 60035 432-8000

No specialized programs for the developmentally disabled.

HYPERACTIVE CHILDREN'S INSTITUTE -- FEINGOLD ASSOCIATION OF ILLINOIS
1755 West Roscoe, Chicago, IL 60657 477-1472 or 472-6744

Parents' organization that provides information and counseling on the Feingold diet that claims to reduce hyperactivity in children.

ILLINOIS ALLIANCE FOR EXCEPTIONAL CHILDREN AND ADULTS

515 West Giles Lane, Peoria, IL 61614 309-691-0256

President: Sally Hoerr

A coalition of smaller organizations whose members include parents and professionals. The groups seek to encourage public awareness of the rights, needs and capabilities of exceptional people.

ILLINOIS ASSOCIATION FOR RETARDED CITIZENS

Ridgely Building, 504 East Monroe, Springfield, IL 62701
217-522-9643 or -9644

Executive Director: Donald Moss

Statewide non-profit organization working on behalf of 340,000 retarded citizens and their families throughout Illinois. Goals include improved care and services for the retarded in areas of prevention, education, residential, vocational, and recreational services, and research. Chicago office at 6 North Michigan Avenue, Chicago, IL 60602, telephone 263-7135.

ILLINOIS BELL TELEPHONE -- SERVICES FOR THE HANDICAPPED

212 West Washington, Chicago, IL 60606 742-4421

Can help disabled persons by equipping them with special phone equipment and teaching them how to use it.

ILLINOIS CHILDREN'S HOSPITAL-SCHOOL

1950 West Roosevelt Road, Chicago, IL 60608 341-6220

A residential, educational and rehabilitation center for children with orthopedic handicaps so severe that their needs cannot be met in the home community or through existing resources. Serves 100 children between 5 and 20 years, nearly half with cerebral palsy. Child must be educable to be admitted to the program. Average stay is 4½ years. Is a rehabilitation center rather than a fully staffed and equipped hospital. Contact Superintendent in care of address above for information. Application should be made to the Department of Rehabilitation Services.

ILLINOIS COMMISSION ON MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

State Capitol Building, Springfield, IL 62706

Composed of 12 Illinois legislators and 7 representatives of the public. Its mandate includes reviewing and making recommendations on policies that affect the mentally ill; developmentally disabled and alcoholic and other substance abusers; and monitoring the Illinois Department of Mental Health and Developmental Disabilities and other agencies that deal with these populations.

ILLINOIS DEPARTMENT OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES SUB-REGION 7 -- DEVELOPMENTAL DISABILITIES' DIVISION

750 South State Street, Elgin, IL 60120 742-1040, ext. 2400.

Director: Richard Hammes

Subregion for the Department which serves the Lake County area. Provides information on available residential placements in state facilities. For admittance to state facilities and for use of the diagnostic facilities at the Illinois Institute for Developmental Disabilities, contact this office.

ILLINOIS DEPARTMENT OF REHABILITATION SERVICES (DRS)

(formerly the Illinois Department of Vocational Rehabilitation, DVR)
2229 Grand Avenue, Waukegan, IL 60085 244-8474

The state agency which provides direct vocational services through its local offices and provides funding for vocational programs through private agencies. Some of the services provided are medical evaluation and treatment, provision of physical aids (artificial limbs) job training and placement, and counseling and guidance. The administrative offices are located at 623 East Adams Street, Springfield, IL 62706.

ILLINOIS DEVELOPMENTAL DISABILITIES ADVOCACY AUTHORITY

1 West Old State Capitol Plaza, Suite 917, Springfield, IL 62701
217-785-1541

Implements the Illinois plan to protect and advocate the rights of the developmentally disabled.

Two advocates serving the Lake County area are Ms. Phyllis Korwin at the Waukegan Developmental Center, Waukegan, IL 60085, and Mr. George Ackron-- IDDAA Advocate, 666 Russell Court, Room 1-B, Woodstock, IL 60098.

ILLINOIS DEVELOPMENTAL DISABILITIES LAW PROJECT

343 South Dearborn Street, Suite 709, Chicago, IL 60604 341-9026

Project Director: Wallace Winter

State funded project through the Illinois Department of Mental Health and Developmental Disabilities which provides free legal counsel to families and organized groups who need legal help in their dealings with handicapped children.

ILLINOIS GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

222 South College, Springfield, IL 62706 217-782-9696

Executive Director: Raymond Ramirez

Mandated by federal law the council is responsible for planning and coordinating services for the developmentally disabled in Illinois.

ILLINOIS INSTITUTE FOR DEVELOPMENTAL DISABILITIES (IIDD)
1240 W. Roosevelt Road, Chicago, IL 60608 341-8000

Provides free multidisciplinary diagnostic, evaluation, and recommendation services to the developmentally disabled upon the referral of the Subregion Coordinator, Chris Moore at the Elgin Mental Health Center, 750 South State Street, Elgin, 60120, 742-1040, ext. 429. Intake worker at IIDD decides whether client should be seen by staff. If case is taken, many services available (for example, medical work-up, psychological, speech and hearing, audiological, vocational rehabilitation counseling, or special education).

ILLINOIS MASONIC MEDICAL CENTER
927 Wellington Avenue, Chicago, IL 60657

Conducts a Dentistry for the Handicapped program available to children under the age of 21 who are developmentally disabled and to adults over the age of 21 who are mentally handicapped. Provides in-patient and out-patient care, phone 525-2300, ext. 651.

ILLINOIS OFFICE OF EDUCATION
100 North First Street, Springfield, IL 62777 217-782-4321

State agency in charge of providing education for all handicapped children ages 3 to 21 in the state of Illinois. Provides information on the rights of handicapped children to an appropriate education and acts as the final arbiter in questions of placement and curricula.

ILLINOIS REGIONAL RESOURCE CENTER
Northern Illinois University, Department of Learning and Development, Graham Hall 245, DeKalb, IL 60115

Regional center for education materials and information dealing with special populations, developmentally disabled persons included. Publishes a newsletter.

ILLINOIS SOCIETY FOR AUTISTIC CHILDREN
730 East Vine Street, Room 211, Springfield, IL 62703

Executive Director: Lana Cooney

Works to increase the public's awareness of the nature of autism, provide information and lobby for legislation to provide special education designed specifically for autistic children.

ILLINOIS STATE JOB SERVICE
150 Genesee Street, Waukegan, IL 60085 662-6913

Provides a listing of jobs open in many different categories. Also provides minimal job counseling. Office also at 74 East Grand Avenue, Fox Lake, IL 60020, phone 587-9200.

IMMACULATE CONCEPTION CHURCH
510 Grand Avenue, Waukegan, IL 60085 623-1850

Provides special religious education.

IMMANUEL BAPTIST CHURCH
1016 Grand Avenue, Waukegan, IL 60085 336-4800

Provides special religious education.

JEWISH FAMILY AND COMMUNITY SERVICE
210 Skokie Valley Road, Highland Park, IL 60035 831-4225

Provides community and life education, homemaker service, home economics, loan funds for emergencies, economic readjustment, vocational and professional education and legal aid to Jewish children and adults.

KENOSHA ACHIEVEMENT CENTER
1218 79th Street, Kenosha, WI 53140 414-658-1687

Evaluation center for vocational skills and sheltered workshop that is available to residents of northern Lake County through the Department of Rehabilitation Services. Provides evaluation in all skill areas for adults, 16 years and older, and a final written evaluation. Buses provide transportation to the workshop for northern Lake County residents.

KLINGBERG SCHOOL
Route 2, Box 312, Mundelein, IL 60060 526-2176

Director: Irene Klingberg

Residential school for ambulatory developmentally disabled children ages 6 to 21. In addition to special education services there is a prevocational workshop and sheltered workshop.

LAKE COUNTY AREA VOCATIONAL CENTER (LCAVC)
19525 Washington Street, Grayslake, IL 60030 223-6681

Extended occupational education for high school juniors and seniors who wish to gain employability in one of a wide range of occupation areas. Funding for training provided by the school district.

LAKE COUNTY BAR ASSOCIATION -- LAWYER REFERRAL SERVICE
244-3140

Provides referrals to persons who need legal service or legal advice to members of the Bar Association.

LAKE COUNTY COMPREHENSIVE EMPLOYMENT AND TRAINING ACT (CETA) PROGRAM

307 West Washington Street, Waukegan, IL 60085 249-2200

Federally funded program which provides a variety of vocational and training opportunities through development of jobs in the public and private sectors. Services provided include: on-the-job training in vocational careers, supportive services such as day care, transportation allowances, counseling, and employment through local government agencies or non-profit organizations.

LAKE COUNTY COORDINATING COUNCIL FOR MENTAL HEALTH, SUBSTANCE ABUSE, AND DEVELOPMENTAL DISABILITIES

Lake County Board of Health, 3010 Grand Avenue, Waukegan, IL 60085
689-6700

The new council (Fall 1979) is charged with examining the service needs of all the groups in its title and developing a comprehensive county plan for all those groups. It will review all Lake County requests for funding from the Illinois Department of Mental Health and Developmental Disabilities. The council will be composed of consumers and providers--both direct service and funding.

LAKE COUNTY CRIPPLED CHILDREN, INC.

322 O'Plaine Road, Gurnee, IL 60031 336-7624

Administrator: Catherine Dietmeyer

Consultation and treatment of orthopedic problems by an orthopedic specialist. Children under 16 are eligible for the monthly clinic that is free of charge.

LAKE COUNTY DEPARTMENT OF PUBLIC AID

114 South Genesee, Waukegan, IL 60085 336-5212

Administers State of Illinois funded programs such as the following: Aid to Families and Dependent Children, Food Stamps, and Medicaid. Answers questions about public aid.

LAKE COUNTY HEAD START

574 McAlister Street, Waukegan, IL 60085 244-0043 or -0044

Director: Thera Ramos

Federally funded preschool centers offering complete and comprehensive medical and dental care, psychological and social services to the child and/or family, 2/3 of each child's daily nutritional requirements, and free transportation to and from school. By law Head Start populations must include 10 to 15 percent students with handicaps.

LAKE COUNTY HEALTH DEPARTMENT
3010 Grand Avenue, Waukegan, IL 60085 689-6700

Executive Director: Dr. Steven Potsic

Provides a full range of medical, dental, educational and psychological services to residents of Lake County. Some of the services offered are community dentistry, health education, immunization clinics, a variety of nursing services, and mental health and substance abuse programs.

LAKE COUNTY PHYSICIAN'S REFERRAL OF THE LAKE COUNTY MEDICAL SOCIETY
226 Genesee Street, Waukegan, IL 60085 662-7766

Provides names of doctors in good standing with the society who are accepting patients.

LAKE COUNTY SOCIETY FOR THE RETARDED
Robert A. Flood Work Activity Center, 2713 Deborah, Zion, IL 60099
872-5557

Director: Robert A. Flood

Provides a work activity and sheltered workshop program for developmentally disabled, emotionally disturbed and physically handicapped adults over 16 years of age.

LAKE COUNTY SPECIAL EDUCATION ADVISORY COMMITTEE
A904 County Building, Waukegan, IL 60085 689-6313

The Advisory Committee appointed by the Lake County Regional Superintendent of Schools, William Thompson, is responsible for the development, evaluation and overall coordination of Lake County's Master Plan for Special Education. Other responsibilities include interpreting State policy for special education, planning future service delivery and policy for special education districts, and making recommendations to the superintendent. Meets quarterly.

LAKE FOREST HOSPITAL
660 Westmoreland, Lake Forest, IL 60045 234-5600

Do not provide primary diagnoses but will do lab tests on a physician's request. They have an audiology department for complete audiological testing and a speech therapy program for treatment.

LAKE-McHENRY REGIONAL PROGRAM (LMRP)
4440 Grand Avenue, Gurnee, IL 60031 623-0021

Executive Director: Mary Budzik

Provides a variety of services to residents of Lake and McHenry counties under the age of 21 including: a parent-infant educational program for the early identification and treatment of developmental delays; diagnostic services such as audiological, psychological, vision, and physical and occupational therapy; and a Regional Educational Materials and Information Service (REMIS) which gathers and disseminates data for teachers, but may be used by parents interested in curricula and media materials.

THE LAMBS, INC.
P.O. Box 520, Libertyville, IL 60048 362-4636

A private, non-profit organization providing semi-protective employment and vocational training for community placement for mildly and moderately developmentally disabled adults over the age of 18. Residential facilities by Spring 1980 will accommodate 37 moderately handicapped adults and 113 mildly handicapped adults.

THE LEARNING EXCHANGE
424 Lee Street, Evanston, IL 60202 273-3383

Service group that matches teachers, tutors, and students by phone so that they can exchange knowledge, learn skills, share interests. Over 2,500 different subjects listed in the catalog. Yearly membership fees entitles one to unlimited use.

LITTLE CITY FOUNDATION
P.O. Box 900, Palatine, IL 60067 358-5510

Superintendent: Donald Becker

Residential school for developmentally disabled children and adults. At this time it is only admitting children ages 6 to 21 who are ambulatory. Offers a community social habilitation program for children and adults with disabilities from Little City and from the community.

LOW INCIDENCE COOPERATIVE AGREEMENT (LICA)
8257 Harrison Street, Niles, IL 60648 679-7950

In addition to services to the blind and deaf children, provides an early intervention program for children from birth to three years old living in the Northern Suburban Special Education District (NSSED).

LOYOLA UNIVERSITY MEDICAL CENTER
2160 South First Avenue, Maywood, IL 60153

Multiple services:
(1) Perinatal Center for newborn children with critical troubles (such as prematurity and birth defects) and a program which follows up on children who were in perinatal center. (531-3499).

(2) Epilepsy Clinic at the Specialty Pediatrics Clinic. Held the fourth Thursday of every month at 9 a.m. for children under 16 years of age. General neurological exam, blood level tests and follow-ups. First visit $75, sliding fee scale and public aid accepted. For appointments call: 531-3831.
(3) Specialty clinics for scoliosis (curvature of the spine) and spina bifida.

LUTHERAN GENERAL HOSPITAL
1775 Dempster, Park Ridge, IL 60068 696-2210

Multiple services:
(1) Perinatal Center for newborn children with critical troubles (such as prematurity and birth defects).
(2) Developmental Abilities Service, Ambulatory Care Center, 1775 Ballard Road, Park Ridge (696-5880), Dr. Peter DeVryer, Director. Comprehensive multi-disciplinary testing and diagnosis center including treatment, therapies and counseling for children with developmental learning or behavioral problems. Fees: $200-600.
(3) Genetic Counseling, Dr. Carol Booth, 696-7700

MARKLUND HOME
164 South Prairie, Bloomingdale, IL 60108 529-2871

A private residential facility serving nonambulatory children functioning at the severe and profound levels of retardation from birth through eighteen years of age.

McHENRY COUNTY ASSOCIATION FOR RETARDED CITIZENS
1005 McHenry Avenue, Woodstock, IL 60098 815-338-5584

Provides many different services to McHenry County residents, some of which are available to Lake County residents. A vocational evaluation center in Woodstock screens prospective adult clients for two rehabilitation workshops located in the county. The association also sponsors a community living facility in Woodstock for twenty developmentally disabled adults. The association offers respite care to Lake and McHenry residents.

McHENRY HOSPITAL
McHenry, IL 60050 815-385-2200

No specialized programs for the developmentally disabled.

MEDI-CHECK INTERNATIONAL FOUNDATION, INC.
2640 Golf Road, Glenview, IL 60025 724-8280

Provides stainless steel emergency medical identification neck tags, wrist bracelets and metal wallet cards for those with hidden medical problems (such as allergies to medications or seizures).

MERCY HOSPITAL AND MEDICAL CENTER
Stevenson Expressway at King Drive, Chicago, IL 60616

Pediatric-Child Development Clinic. Provides multidisciplinary diagnosis and assessment for children with epilepsy, mental retardation, cerebral palsy and other disorders. Services include: complete physical examination, patient and family counseling, psychological, occupational and physical therapy, speech therapy, and audiological. Sliding fee scale and green card accepted. For referral to clinic call: Dr. Eappen, M.D. at 567-5575. For more information call: 567-2128.

MESSIAH LUTHERAN CHURCH
200 Ivanhoe Road, Wauconda, IL 60084 526-7161

Provides special religious education.

MICHAEL REESE HOSPITAL AND MEDICAL CENTER
2929 South Ellis, Chicago, IL 60616

Several Programs:
(1) Dysfunctioning Child Center (791-4230). Coordinates multidisciplinary, medical and educational evaluations and treatment for children under 16. Complete evaluation requires about 3 weeks of out-patient testing. Follow-up treatment program available. 0-6 month waiting list. Referrals must be made by professional source (school, physician or social welfare agency, for example). Sliding fee scale; green card accepted.
(2) Neuromuscular Disabilities Program. Has four clinics: (a) neuromuscular (such as cerebral palsy), (b) neurocutoneous (genetically-caused skin problems), (c) spina bifida and (d) muscular dystrophy. In-patient facilities and outpatient treatment for consultation, diagnosis, evaluation and referral. Multidisciplinary evaluations focusing on medical diagnosis. Open to persons of all ages. Outpatient clinics run several times a month. Sliding fee scale available. Green card accepted.
(3) Siegel Institute for Communicative Disorders, 3033 South Cottage Grove Avenue, Chicago 60616
Multidisciplinary diagnoses and evaluation for children with speech and language impairment or delay, children demonstrating severe developmental delay with sensory disabilities, and hearing impaired due to a developmental disability. In addition to seeing, communicative disorder expects child is evaluated by others, including neurologist and occupational therapist. Services available for person of any age. Sliding fee available. Green card accepted.
(4) Mandel Dental Clinic. For appointments call: 791-2780.
Screens children from other Michael Reese programs and screens and treats handicapped individuals in the outpatient clinic and in an operating room setting as deemed appropriate by the screening dentist. Full-time dental hygienist participates in oral hygiene and disease control instruction with the handicapped and their guardians.

MISERICORDIA NORTH
6300 North Ridge Boulevard, Chicago, IL 60660 973-6300

Residential school for 69 developmentally disabled children ages 2 to 18. However, at this time children must be under the age of 12 to be admitted. Children must be ambulatory.

MORAINE ASSOCIATION
P.O. Box 341, Highland Park, IL 60035 433-3182

Executive Director: Lee Kranig

Community living facility for 20 developmentally disabled adults who are employable in community jobs.

MOUNT SAINT JOSEPH
Route 3, P.O. Box 365, Lake Zurich, IL 60047 438-5050

Director: Sister Margaret Vogel

Residential facility for 160 adult developmentally disabled females, ages 18 or over.

NATIONAL ASSOCIATION FOR DOWN'S SYNDROME (NADS)
P.O. Box 63, Oak Park, IL 60303 369-7739

Disseminates information, seeks to develop the potential of persons with Down's Syndrome, and encourages community acceptance, research, and better programs. Publishes a newsletter and a selected list of references.

NATIONAL ASSOCIATION FOR RETARDED CITIZENS (NARC)
P.O. Box 6109, 2709 Avenue E East, Arlington, TX 76011

Promotes the welfare of mentally retarded people and works for improved care, treatment, training, education, public education and integration of community and residential programs. Provides information and materials. For news on the latest legislation and trends write to Governmental Affairs Office, NARC, Suite 516, 1522 K Street N.W., Washington, D.C. 20005.

THE NATIONAL EASTER SEAL ASSOCIATION FOR CRIPPLED CHILDREN AND ADULTS
2023 West Ogden Avenue, Chicago, Il 60612

Through its local chapters and centers provides direct service to handicapped individuals in programs such as camps, transportation services, equipment loan, information, referral and follow-up, sheltered workshops and special education. Advocates for the handicapped through legislative activity, carries out public education programs and supports research.

NATIONAL FOUNDATION -- MARCH OF DIMES

Metropolitan Chicago Chapter, 53 West Jackson Boulevard,
Chicago, Il 60604 341-1370

Provides information services and referrals to families with children who have birth defects. Information and materials available on how to prevent or minimize birth defects. Information hotline telephone number, 263-1200.

NATIONAL FOUNDATION OF DENTISTRY FOR THE HANDICAPPED

1726 Champa Street, Suite 422, Denver, CO 80202

Provides information on the latest techniques in dentistry for the handicapped, lists dentists by state and community who serve the handicapped, and provides materials for parents and professionals on proper dental care.

NATIONAL SOCIETY FOR AUTISTIC CHILDREN (NSAC)

169 Tampa Avenue, Albany, NY 12208 515-489-7375

National parents' organization provides publications, book lists, and information. NSAC's Information and Referral Service, 306 31st Street, Huntington, WV 25702, phone 304-697-2638.

NORTH SHORE ASSOCIATION FOR RETARDED CITIZENS

2525 Church Street, Evanston, IL 60201 869-6610

In addition to other programs provides two workshops for developmentally disabled adults and a community living facility.

NORTH SHORE HELP LINE

P.O. Box 1001, Highland Park, IL 60035 945-0670

Hot line service for persons living in Deerfield and West Deerfield Townships in Lake County, phone 945-8822.

NORTH SUBURBAN SELF HELP CENTER

755 Laurel Lane, Highland Park, IL 60035 433-4130

Serves predominantly Spanish-speaking persons from southern Lake County with services, such as English classes for non-English speaking persons, referrals to proper agencies, free or reduced cost medical help, transportation for medical, emergency appointments and interpreters. The phone number is a 24-hour emergency line.

NORTH SUBURBAN SYNAGOGUE -- BETH EL

1175 Sheridan Road, Highland Park, IL 60035 432-8900

Provides special religious education.

NORTHEASTERN ILLINOIS SPECIAL RECREATION ASSOCIATION (NISRA)
P.O. Box 708, Waukegan, IL 60085 249-3000

Provides special recreation programs and activities.

NORTHERN ILLINOIS CHAPTER -- AMERICAN SOCIETY FOR PSYCHOPROPHYLAXIS IN OBSTETRICS, INC. (LAMAZE)
P.O. Box 174, Highland Park, IL 60035 433-5550

Provides information on the Lamaze method of child delivery and lists teachers of classes in different communities.

NORTHERN ILLINOIS SPECIAL RECREATION ASSOCIATION (NISRA)
1C Crystal Lake Plaza, Crystal Lake, IL 60014 815-459-0737

Provides special recreation and activities.

NORTHERN SUBURBAN SPECIAL EDUCATION DISTRICT (NSSED)
760 Red Oak Lane, Highland Park, IL 60035 831-5100

Superintendent: Dr. Stanley T. Bristol

Provides special education services to any student age 3 to 21 who lives in an area from Wilmette to Lake Bluff, including the southeastern portion of Lake County, and part of Cook County. Services provided include diagnostic, outreach, consultative, educational and support services for students. Services are provided in classroom of regular attendance centers and at a centrally located diagnostic center and school for the moderately handicapped, Stratford School.

NORTHERN SUBURBAN SPECIAL RECREATION ASSOCIATION (NSSRA)
760 Red Oak Lane, Highland Park, IL 60035 831-2450

Provides special recreation and activities.

NORTHWEST SUBURBAN AID FOR THE RETARDED
65 East Palatine Road, Wheeling, IL 60090 541-5250

Runs a work activities program for the developmentally disabled called Palwaukee Industries. For adults, 16 years and older.

NORTHWESTERN SPECIAL RECREATION ASSOCIATION (NWSRA)
600 North Ridge, Arlington Heights, IL 60004 394-4948

Does not include any Lake County Communities but may be worthwhile for residents of southwestern Lake County, if no other programs are available.

NORTHWESTERN UNIVERSITY -- FRANCES SEARLE BUILDING
2299 Sheridan Road, Evanston, IL 60201

Provides clinical services in audiology and hearing impairment, phone 492-3165, and in speech and language, phone 492-5012, under the direction of the Communicative Disorders Department.

NORTHWESTERN UNIVERSITY MEMORIAL HOSPITALS
303 East Superior Street, Chicago, IL 60611

Multiple services provided by several hospitals which make up the medical complex. Two services are: Perinatal center for newborn children with critical troubles (such as prematurity and birth defects) located at the Prentice Women's Hospital, 649-7575, and Epilepsy Clinic - provides ongoing physical, neurological and psychological treatment for persons with epilepsy. Contact Dr. Richard Rovner, 649-7950.

OPPORTUNITY, INC.
777 Central Avenue, Highland Park, IL 60035 433-6300

President: John Cornell

A not-for-profit corporation offering employment and training to people sixteen years of age and older who are developmentally disabled, emotionally disturbed, or physically handicapped. Handicapped and non-handicapped employees work together in a competitive work environment to produce marketable products at competitive prices.

ORCHARD VILLAGE
7670 Marmora, Skokie, IL 60077 967-1800

Executive Director: Bernard Saltzberg

Community living facility and respite care program for 42 developmentally disabled adults capable of employment in the community.

PARENTAL STRESS SERVICES (CITIZENS' COMMITTEE FOR CHILDREN AND PARENTS UNDER STRESS)
64 East Jackson Boulevard, Chicago, IL 60604 427-1161

Provides a 24-hour hotline for parents and children under stress, phone 463-0390, an outreach program used to develop important relationships with troubled parents, a referral service to community services and resources, and a group called Parents Anonymous where parents meet to help reach solutions to common problems in a private and informal atmosphere.

PARENTS' CAMPAIGN FOR HANDICAPPED CHILDREN AND YOUTH
P.O. Box 1492, Washington, D.C. 20013

A national center for information on handicapped children and youth. Publishes COMMON SENSE FROM CLOSER LOOK.

PATIENT PRESCRIPTION INFORMATION, INC.

5942 South Central Avenue, Chicago, IL 60638   582-1173

A service product, designed to improve understanding of drugs and compliance in use of medications, is marketed by this company. For example, see page 57.

PEACOCK CAMP FOR CRIPPLED CHILDREN

509 Deep Lake Road, Lake Villa, IL 60046

Provides organized camping experience for physically handicapped children during the summer. Call 356-5201--Summer; 356-3931--Winter.

PRESBYTERIAN-ST. LUKE'S HOSPITAL

1753 West Congress Parkway, Chicago, IL 60612

Can provide complete diagnostic services through the Pediatrics Department. Also has Birth Defects Special Treatment Center offering complete, coordinated, comprehensive, multidisciplinary care for children with birth defects, 942-6398.

PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED

Washington, D.C. 20201

Permanent presidential committee which provides information and policy suggestions for the employment of handicapped people.

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

Washington, D.C. 20201

Permanent presidential committee which provides information and materials to the public and publishes a newsletter, P.C.M.R. NEWSBREAK.

RAY GRAHAM ASSOCIATION'S CAMP ST. FRANCIS

266 West Fullerton Avenue, Addison, IL 60101

Summer camp located in Libertyville and sponsored by the Ray Graham Association for children and adults. Call James Husch at 325-3857.

REGIONAL TRANSPORTATION AUTHORITY

2504 Washington, Waukegan, IL 60085

Provides a reduced fare program for handicapped persons who apply for a traveler's card. For travel information call 800-972-7000. For information on reduced fares write to the Reduced Fare Program, Regional Transportation Authority, P.O. Box 3858, Chicago, IL 60654.

REHABILITATION INSTITUTE OF CHICAGO

345 East Superior Street, Chicago, IL 60611 649-6000

Devoted entirely to the rehabilitation of physically disabled persons of all ages.

RIVERSIDE FOUNDATION
Route 1, P.O. Box 158 Mundelein, IL 60060 634-3973
Executive Director: Pete Mulé

An intermediate care facility for developmentally disabled adults ages 18 and over. Admission is open to ambulatory persons. Vocational programs available from community workshops.

ROCKFORD MEMORIAL HOSPITAL
2400 North Rockton Avenue, Rockford, IL 61101 815-968-6861

Has a perinatal center for newborn children with critical troubles (such as birth defects and prematurity).

SAINT ANDREW'S LUTHERAN CHURCH
10 South Lake Street, Muldelein, IL 60060 566-8081

Provides special religious education.

SAINT COLETTA
Jefferson, WI 53549 414-674-4330

Administrator: Sister Mary Sheila

Facilities include residential school for developmentally disabled children ages 6 to 21, a training center for disabled young adults with vocational training and on-the-job experience, residential facilities and sheltered employment for adults.

SAINT DISMAS CHURCH
2600 Sunset Avenue, Waukegan, IL 60085 244-9511

Provides special religious education.

SAINT JOSEPH CHURCH--LIBERTYVILLE
130 Hurlbert Court, Libertyville, IL 60048 362-5797

Provides special religious education.

SAINT JOSEPH CHURCH--ROUND LAKE
114 North Lincoln Avenue, Round Lane, IL 60073 546-3610

Provides church services for the deaf every Sunday.

SAINT MARY'S CHURCH--BUFFALO GROVE
75 North Buffalo Grove Road, Buffalo Grove, IL 60090

Provides special religious education.

SAINT MARY'S CHURCH--LAKE FOREST
175 East Illinois Road, Lake Forest, IL 60045 234-0205

Provides special religious education.

SAINT THERESE HOSPITAL
2615 Washington, Waukegan 60085 688-5800

No specialized programs for the developmentally disabled.

SANTA MARIA DEL POPOLO
126 North Lake Street, Muldelein, IL 60060 566-7340

Provides special religious education.

SCHWAB REHABILITATION HOSPITAL
1401 South California Avenue, Chicago, IL 60608

Provides rehabilitation programs for physically handicapped children and adults, specializing in diseases of the nervous, muscular and skeletal systems (such as cerebral palsy).

SELF-HELP DEVELOPMENT INSTITUTE
Center for Urban Affairs, Northwestern University, Evanston, IL 60201
492-3395

Director: Dr. Leonard Borman

The Institute grew out of efforts to identify, study and assist self-help, mutual aid and human support groups in such fields as health, mental health, education, and economic and community development. The Institute has five facets: research, education and training, workshops, policy studies, and a clearinghouse for publications and coordination of activities. The Epilepsy Self-Help Group Workshop publishes a quarterly newsletter through the Institute.

SHRINER'S CRIPPLED CHILDREN'S HOSPITAL
2211 North Oak Park Avenue, Chicago, IL 60635

Provide free in- and out-patient care to children under the age of 16, who have physical disabilities and handicaps, no matter what their mental abilities are. Many of the patients served are post-operative cases who need therapy and constant medical attention, 622-5400. National office of the Shriner's is at 323 North Michigan Avenue, Chicago, IL 60601, 346-8323.

SOCIAL SECURITY ADMINISTRATION
2500 West Grand Avenue, Waukegan, IL 60085 244-5050

Assists persons applying for social security benefits, including Medicare and Supplemental Security Income. Answers questions on social security.

SOCIETY FOR THE PROTECTION OF THE UNBORN THROUGH NUTRITION (SPUN)
17 North Wabash Street, Chicago, IL 60602 332-2334

Provides information and educational materials on prenatal nutrition and provides prenatal nutrition training.

SPECIAL EDUCATION DISTRICT OF LAKE COUNTY (SEDOL)
4440 Grand Avenue, Gurnee, IL 60031 623-0021

Superintendent: L.D. Vuillemot

Provides special education services to any student age 3 to 21 who lives in northern, central and southwestern Lake County. Services provided include diagnostic, outreach, consultative educational and support services for students. Services are provided in classrooms of regular attendance centers and at a centrally located diagnostic center and school for the moderately retarded, Laremont School.

SUBREGION 7 DEVELOPMENTAL DISABILITIES SERVICES ACT (DDSA) PLANNING COMMITTEE
188 South Northwest Highway, Cary, IL 60013 639-0061

Contact: Mark Mayo

Organized for the purpose of developing a comprehensive plan for services to the developmentally disabled in Subregion 7 of the Department of Mental Health and Developmental Disabilities, which includes Lake County. At times, subgroups form to concentrate on certain issues, such as the Lake County DDSA Committee.

TRINITY COLLEGE
2045 Half Day Road, Deerfield, IL 945-6700

4-year private college. Offers courses in special education along with the degree program in elementary education; graduates then apply directly to the State for certification in teaching special education. In addition to enrolling in the regular degree program, persons can take one or more courses either for credit or by auditing. Types of courses offered are: characteristics of children with learning disabilities, psychology of exceptional children, education of children with learning disabilities, diagnostic testing for learning disabilities, tests and measurements, student teaching for special education. Students enrolled in these courses might also be available as babysitters or companions.

UNITED CEREBRAL PALSY OF GREATER CHICAGO
343 South Dearborn Street, Room 1810, Chicago, IL 60604 922-2238

Provides programs in leisure and self-expressions, a day camp in Gurnee and educational and therapy facilities for children. Will provide information and selected reading. National office: United Cerebral Palsy Associations, Inc., 66 East 24th Street, New York, New York 10016, phone 212-889-6655.

UNITED WAY OF LAKE COUNTY, INC.
Room 201, Belvidere Office Plaza, 2835 Belvidere Street, Waukegan, IL 60085
662-3580

A voluntary association of individuals, private and public agencies, civic and professional organizations, and others for the purpose of uniting and coordinating agencies or groups interested in or providing educational, health, recreational, and social welfare services. Is a major source for funding, policy planning, and program review in the county.

UNIVERSITY OF ILLINOIS HOSPITALS
840 South Wood, Chicago, IL 60612

Conglomeration of hospitals and specialty clinics which are not necessarily interrelated or coordinated. Complete medical diagnoses can be handled by the Pediatric Clinic, 996-7416. The Neurological Clinic conducts a comprehensive program for persons with epilepsy under the age of 21, 996-6496. For information on any of the specialty clinics, 996-6816.

VETERAN'S ADMINISTRATION HOSPITAL
Buckley Road, North Chicago, IL 60064   689-1900

No specialized programs for the developmentally disabled.

VICTORY MEMORIAL HOSPITAL
1324 N. Sheridan, Waukegan, IL 60085   688-3000

No specialized programs for the developmentally disabled.

WAUKEGAN COMMUNITY UNIT SCHOOL DISTRICT #60 -- SPECIAL EDUCATION SERVICES
1201 North Sheridan Road, Waukegan, IL 60085   336-3100, ext. 434

Director of Special Education: William E. Vickers.

Provides special education services to any student age 3 to 21 who lives in Waukegan Community Unit School District #60. Services provided include diagnostic, outreach, consultative educational and support services for students. Services are provided in classrooms of all the district's schools and at a centrally located diagnostic center and school, the Lincoln Center.

WAUKEGAN DEVELOPMENTAL CENTER
Dugdale Circle, Waukegan, IL 60085   249-0600

Superintendent: Patrick Saunders

A state residential facility for ambulatory severely and profoundly retarded children and adults, from age six on. Provides full range of education, training, living and care programs. Library is available for use by any Illinois resident. Resident chaplain, Reverend Darryl Anderson provides special religious education for residents and any developmentally disabled persons and their families in the community.

WYLER'S CHILDREN'S HOSPITAL OF THE UNIVERSITY OF CHICAGO
950 East 59th Street, Chicago, IL 60637

Multiple services: (1) Pediatric epilepsy clinic for children provides ongoing treatment of epilepsy by coordinating medical and educational treatment, 947-6225.
(2) Diagnostic Clinic for Infants and Children, 947-6248.
(3) Complete medical, educational and psychological evaluations performed, 947-1000.

YMCA -- BUEHLER
Northwest Highway and Countryside Drive, Palatine, IL 60067

YMCA -- LEANING TOWER
6300 Touhy Avenue, Niles, IL 60648

YMCA -- NORTH SUBURBAN
2705 Techny Road, Northbrook, IL 60062

YMCA -- NORTHWEST SUBURBAN
300 Northwest Highway, Des Plaines, IL 60016

All of the above YMCA's are located near Lake County and have special classes and programs for the developmentally disabled.

OTHER YMCA and YWCA
YMCA of Greater Lake County -- South Genessee Street Branch
655 South Genesee Street, Waukegan, IL 60085

YMCA of Greater Lake County -- Central Branch
204 North County Street, Waukegan, IL 60085

YMCA -- Central Lake Family
424 North Prospect, Mundelein, IL 60060

YWCA -- Waukegan
445 North Genesee, Waukegan, IL 60085

YWCA -- Lake-Cook
755 Laurel Avenue, Highland Park, IL 60035

All of the above have no special programs for the developmentally disabled but would accept them into their regular programming.

YOUTH AND FAMILY COUNSELING
1125 North Milwaukee Avenue, Libertyville, IL 60048   362-5991

Counseling by qualified psychiatric social workers and psychologists to individuals and families concerning parent-child, marriage, and individual problems. Available to residents of Ela, Fremont, Libertyville, and Vernon Townships in Lake County.

ZION-BENTON (AMERICAN INTERNATIONAL) HOSPITAL
Shiloh Blvd., Zion, IL 60099   872-4561

No specialized programs for the developmentally disabled.

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